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The Role of the Community Clinical Nurse Specialist in Palliative Care in the South of Ireland

Eileen Gobnait O'Leary

A thesis submitted for the degree of Professional Doctorate in Health

University of Bath

School for Health

September 2015

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ABSTRACT

Clinical Nurse Specialism was established in Ireland in 2001. As this new role has become embedded in practice over the past decade it has faced a number of challenges. The unsatisfactory articulation of the nature of the work at the level of clinical nurse specialist was described by Seymour et al (2002). The aim of this study was to establish a clear insight and understanding of the role of the Community Clinical Nurse Specialist in Palliative Care (CNSPC) in the South of Ireland. As many studies have examined the CNS role from within the profession, of particular importance here were the perspectives held by patients, family members, and other healthcare professionals.

A qualitative approach through a combination of focus group and semi-structured interviews were held with a range of health care professionals including five focus groups of CNSPC, two General Practitioners (GPs), three focus groups of Public Health Nurses (PHNs) and a nurse representative of the National Council for the Professional Development of Nursing and Midwifery (NCNM) was used. Through purposive sampling four patients and three family members consented to participate in face to face semi-structured interviews on invitation by their CNSPC. Non participant observation was conducted at two team meetings. Thematic analysis (Braun and Clarke, 2006) of the data was undertaken in an attempt to understand the perception of the patients, family members and healthcare professionals.

Three themes emerged following analysis. These were journey as a metaphor, aspects of care and role. From the time of referral to palliative care in the community the CNSPC accompanied the patient on their journey. The CNSPC joined the GPs and PHNs to establish a connection in an effort to guide the patient and family members on the path to their destination. Aspects of care featured the concern, regard and mindfulness of the CNSPC through caring and supporting the patient and family members. In addition, these aspects of care incorporated the team and were delivered through teamwork. The final theme was role, including the elements of role structure and role model. Though role structure captured both the expected and enacted role of the CNSPC, role ambiguity was also encountered. Role conflict and strain were represented as an expressive role but were also accompanied by the interpersonal contact essential to individual relationships.

Recommendations of this study included the clarification of the role of the CNSPC and subsequent dissemination to relevant personnel. By considering solutions that can be achieved will assist the CNSPC in addressing areas of the role that are not being realised. This also included the establishment of a link with academic departments. In conjunction with the PHN service the examination of a “shared plan of care”.

Abbreviations

ANA - American Nurses Association

ANP - Advanced Nurse and Midwife Practitioner CNA – Canadian Nurses Association

APN – Advanced Practice Nursing

CNA – Canadian Nurses Association

CNC – Clinical Nurse Consultant

CNS – Clinical Nurse Specialist

CNSPC – Clinical Nurse Specialist in Palliative Care in the Community

CSPCNs - Community Specialist Palliative Care Nurses

GP – General Practitioner

HSE – Health Service Executive

IAPC – Irish Association for Palliative Care

ICS – Irish Cancer Society

IHF – Irish Hospice Foundation

MDT - Multidisciplinary team

NACNS - National Association of Clinical Nurse Specialists

NACPC – Report of the National Advisory Committee in Palliative Care

NCAT - National Cancer Action Team

NCNM – National Council for the Professional Development of Nursing and Midwifery

NICE - National Institute for Health and Care Excellence

PHN – Public Health Nurse

PREP - Post Registration Education and Practice (PREP)

RCN – Royal College of Nursing

RCT – Randomised Control Trial

RGN – Registered General Nurse

UK – United Kingdom

UKCC - United Kingdom's Central Council for Nursing Midwifery and Health Visiting

USA – United States of America

Glossary of terms

Palliative Care:

“Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications”.

www.who.int/cancer/palliative/definition/en/ retrieved on 18th March 2015

Specialist palliative care services

“Specialist palliative care services are those services with palliative care as their core speciality and which are provided by an inter-disciplinary team, under the direction of a consultant physician in palliative medicine”.

(Department of Health and Children (DoHC), 2001: p.21).

Primary Care

“Primary care is an approach to care that includes a range of services designed to keep people well, from promotion of health and screening for disease to assessment, diagnosis, treatment and rehabilitation as well as personal social services. The services provide first-level contact that is fully accessible by self-referral and have a strong emphasis on working with communities and individuals to improve their health and social well-being”. (DoHC, 2001a: p.15)

Primary Care Team

“Primary care will be centred on the needs of individuals and groups of people and will match their needs with the competencies required to meet them. Some of the essential competencies will include assessment, diagnosis, therapy, nursing, midwifery, prevention, health education, counselling, administration, management, social services, referral and rehabilitation”. (DoHC, 2001a: p.22)

Primary Care Network

“It is envisaged that a wider network of health and social care professionals will be formed who will work with a number of primary care teams. Each primary care team will have access to a range of health and social care professionals who will provide services for members of their enrolled population group. Members of the network will work with more than one primary care team. Formal communications processes will be established between the core primary care team and the wider network of professionals. Named members of the primary care network will be designated to work with specific primary care teams”. (DoHC, 2001a: p.23)

Chapter 1 Introduction

1.0 Introduction

This chapter provides an introduction to palliative care nursing in the community. I begin by providing a background to the thesis. Following this I introduce the justification for the thesis, initially presenting clinical nurse specialism and then clinical nurse specialism in palliative care. This is then followed by the format for the thesis and details the contents of each of the chapters. In conclusion a summary of this chapter is presented.

1.1 The background of this thesis.

A longstanding interest and commitment, together with my experience and background in Palliative Care Nursing served as my initiative and motivation towards examining *The Role of the Community Clinical Nurse Specialist in Palliative Care*. Both my palliative care and nursing background have firmly been embedded in the South of Ireland for the past twenty five years from my early days as a Registered General Nurse (RGN), to a Community Clinical Nurse Specialist in Palliative Care (CNSPC), and finally to a Director of Nursing (Palliative Care). Currently I hold an administration position in the health services with responsibility for Palliative Care.

The Report of the Commission in Nursing: A Blueprint for the future (Government of Ireland, 1998) recommended the introduction of a clinical career pathway for nurses with the development of Clinical Nurse Specialist (CNS) posts. Palliative Care was one such specialist area recognised by the report. Following the establishment of the National Council for the Professional Development of Nursing and Midwifery (NCNM) in 1999, this career structure and specialist pathway was realised. Over the intervening years the evolution of the pathway progressed from “Immediate” to “Intermediate” to the present “Future” pathway (NCNM, 2008).

The resulting changes for palliative care nursing in the community formed the origin and provided the impetus for this study. My practice based understanding and experience of the role of the Home Care Nurse and subsequently the CNS was also an important influence. Within my present managerial role, the focus of my interest was on the recent CNS role development in Palliative Care in Ireland. There has been a lack of knowledge on its implementation, outcome, success and challenges. Some of this may be unique to Palliative Care and I decided to examine this. In addition, during the time of this study the

Irish health service experienced budget cuts and a government moratorium was applied to recruitment which further impacted on the development of advanced nursing roles.

1.2 Justification for thesis – Clinical Nurse Specialism

In the United States of America (USA) the notion of a specialist in clinical nursing was described as early as the 1940s by Peplau (1965) with the development of CNS in psychiatry. The purpose of the CNS role was to improve patient care by direct practice, role modelling and education of others towards this goal (Hamric and Spross, 1983: 1989). From those early days there was an inference that the CNS role was to provide some direct service with a “greater amount of time spent in consultation, education and counselling others who are providing direct care” (Kitzman, 1983).

In the United Kingdom (UK) the concept was developed in the 1980s, leading to the emergence of new posts (Raja-Jones, 2002). In 1994 the United Kingdom’s Central Council for Nursing Midwifery and Health Visiting (UKCC) initially defined specialist practice. However, the UKCC most recent standards in 2001 (p.1) defined specialist practice where “Specialist practice is the exercising of higher levels of judgement, discretion and decision making in clinical care”.

In Ireland it was 2001 (p.9) before the NCNM defined a Clinical Nurse/Midwife specialist as “a nurse/midwife specialist in clinical practice who has undertaken formal recognised post-registration education in his/her area of specialist practice at higher diploma level”. Therefore historically Ireland’s progress in clinical nurse specialism is very much in its infancy compared to the USA and UK development. However, this has provided an opportunity for Ireland to learn from the experiences of other countries in the development of advanced nursing positions and the role of CNS.

Benner (1984) considered the CNS an “expert” in their field, where they provided a rich and dynamic view of clinical expertise together with high analytical and intuitive skills. Being an expert from Hurlimann et al (2001) perspective meant having a wide scope of clinical competence and theoretical knowledge where the knowledge and practice was within a specific context that was considered expert. Graham et al (2006) suggested that the CNS as an expert worked at a higher level of practice and in complex environments. All these attributes differentiated the CNS from the RGN.

Variations were highlighted in the activities and responsibilities of specialist nurses within organisations by Bousfield's investigation into the CNS role in 1997. Reasons attributed to this by Raja-Jones (2002) included the lack of role model, educational preparation, role conflict and role confusion. These variations are of relevance to Ireland in the development of clinical nurse specialism and particularly if learning is to be gained from the experiences of other jurisdictions. Concern was expressed about specialisation in McKenna et al (2003) investigation into generic and specialist nursing roles in the community in Northern Ireland and the Republic of Ireland. These concerns related to role conflict, role overlap and role confusion. In Ireland, the NCNM identified the educational preparation and role description including the five core concepts of clinical focus, patient advocate, education and training, audit and research and consultancy (NCNM, 2008) for the CNS. Challenges were identified by policy makers to the introduction of clinical specialist and advanced practitioner roles (Begley et al, 2014) in the Evaluation of Clinical Nurse and Midwife Specialist and Advanced Nurse and Midwife Practitioner Roles in Ireland (SCAPE) study. These included medical fears and lack of support for the role.

1.2.1 Clinical Nurse Specialism in Palliative Care

Following the recognition of palliative care nursing as a speciality in Ireland and the development of the role of CNS, the title of the "home care" nurse with an expanded role has changed to CNS in Palliative Care (Government of Ireland, 1998; NCNM, 2008). The role of the CNS in Palliative Care encompasses a clinical focus, patient advocacy, education and training, audit and research and consultancy in the care of the specialist palliative care patient and family (NCNM, 2008). The CNS continues to work with health care professionals in the community.

A range of descriptive literature (Black and Farmer, 2013; Jeffreys, 2005; Vidall et al 2011; Wickham 2003) pertaining to the CNS in general is available. Moreover, there is a wealth of accessible literature that is related to the CNS clinical role (Austin et al, 2006; Bamford and Gibson, 2000; Begley et al, 2012; Cattini and Knowles, 1999; Dunn, 1997; Elliott et al, 2012; Glen and Waddington, 1998; Graham et al, 2006; Hunt, 1999; Jokiniemi et al, 2012; Lloyd-Jones, 2005; McKenna et al, 2003; Milner et al, 2006; Nieminen et al, 2011; Wickham, 2013; Willard & Luker, 2007). However, there is a dearth of research specific to the role of the CNS in palliative care as recognised by Husband and Kennedy (2006). Corner et al (2002) evaluated the work of the CNS by collecting and analysing data of what nurses did, their case-mix and the nature of the interventions for patients and carers.

As part of this evaluation Skilbeck and Seymour (2002) undertook an analysis of the CNS work with patients who had complex needs and where Macmillan nurses participated in this comparative case study. Seymour et al (2002) went on to review issues encountered by the CNS where particular problems relating to role ambiguity and role conflict were identified between the Macmillan nurses and their managers. In addition, issues concerning team working and the educative and consultative role were identified.

Chapple et al (2006) wanted to understand from the patient's perspective, the role of the specialist palliative care nurse. In this study patients were found to have valued the nurse's advice and emotional support. However, some patient's expressed concern by the early referral and involvement of the specialist palliative care nurse (Chapple et al, 2006). In an earlier study, Jarrett et al (1999) had sought to examine terminally ill patients' and lay carer perceptions and experiences of community based services. Generally, there was a high level of satisfaction for the services received. However, patients and carers were confused by the job titles and role demarcation of the various nurses in the community involved in their care (Jarrett et al, 1999). Understanding the patient's perspective, as the recipient of the service is of utmost significance and this was of particular importance for me. In addition, discerning the patient and family perspective of the roles of the different nurses in the delivery of care was of relevance. The General Practitioners (GP) who participated in Bajwah and Higginson's (2008) survey in the south east of England were satisfied with their experience and use of palliative care services. Clarification of the roles and responsibilities of the multidisciplinary team (MDT) was an area deemed for improvement. Undoubtedly, the role of the specialist palliative care services is significant in the MDT delivery of care. Indeed, the CNS role within the MDT was also of interest to me.

Of further significance was the recent review conducted by the Cochrane Collaboration in 2013. This presented extensive evidence demonstrating that well over 50% of people preferred to be cared for and to die at home (Gomes et al, 2013; Bell et al, 2009; Higginson and Sen-Gupta, 2000). This evidence was of significance because of the role the CNSPC in facilitating patients who wish to be cared for and to die at home. Studies suggest that between 67% (Weafer and Associates, 2004) and 80% (Tiernan et al, 2002) of the Irish population wish to die at home, but despite this, the IHF (2013) indicated that only 26% of people actually die at home.

With this in mind and being cognisant of the earlier work (Seymour et al, 2002) conducted in the UK in the 2000s, I decided my study needed to be all encompassing and include not

only the CNSPC but other health care professionals, palliative care patients and families in an effort to capture a range of perspectives. I also recognised that I needed to conduct the study in more than one service and elected to include a region spanning 6 services with a population of over 1 million. What was not clear from either practice or literature was the situation in the South of Ireland following the transition from Home Care Nurse to CNS and therefore I decided to explore the role of the CNSPC from a range of individual perspectives.

1.3 Format of the Thesis

This thesis is presented in six chapters which describe the process and progress of the study.

- Chapter two reviews the literature relevant to CNS's in palliative care. This review includes some historical background to the development of CNS, essential elements of the CNS role and the development of CNS in Palliative Care.
- Chapter three describes the qualitative research design. This chapter will also discuss the ontology and epistemology perspectives and the philosophical basis which guided this study. The selection of research methods, sampling strategy, data collection of both the one to one semi-structured interviews and focus group interviews are described. The approach to the data management and analysis through thematic analysis is explained. I will discuss the ethical issues of the study and the importance of reflexivity throughout the research process.
- Chapters four, five and six describe the results and analysis from the semi-structured interviews with the patients and families, the GPs and the Representative of the NCM and the focus group interviews with the CNSPCs and the PHNs. Where appropriate quotations are included to support the analysis as I sought to understand and interpret through thematic analysis what had been said by all the participants about the role of the CNSPC.
- Chapter seven discusses the findings in relation to the known literature in the area. I present new insights and findings from the analysis. The chapter also discusses the limitations of the study. Recommendations for policy and practice, including further research, are discussed. Finally, mechanisms to disseminate the findings of the study are presented.

1.4 Summary

In this chapter I initially provided details of my background, introduced the CNS in Palliative Care in Ireland and explained why I had decided on this area of study. This was followed by examining the development of the CNS in general and then the CNS in Palliative Care and subsequently providing justification for the study. Finally the format of the thesis was presented.

The next chapter will present the literature review.

Chapter 2 Literature Review

2.0 Introduction

This chapter will begin by introducing the literature review. The second section will consider the CNS role development globally and also that pertaining to the Irish context. The third section presents a review of the development of the role. Section four identifies the organisational impact of roles. It examines the literature on teamwork, culture, leadership and communication. Teamwork was chosen as Opie (1997) acknowledged its benefits and how it was influenced by organisational support. Organisational theorists recognised (Parker, 2000) that the success of an organisation was dependent upon culture, values, communication and collaboration. Section five presents the theoretical framework of role theory pertinent to this research study. These sections set the scene for the examination of the specific issues relating to the role of the CNS in palliative care. Section six proceeds to present the evidence relating to the perceptions of the role of the CNS by patient groups and health care professionals. The role of the CNS as educator, change agent and expert practitioner were evaluated. These were identified by Hamric (1989) as further defining the CNS role. Section seven identifies the challenges encountered by the CNS. It is followed by section eight which illustrates where future research will be focused and concludes with the research question, aims and objectives.

Early developments in nursing have been dependent on the vision, creativity and charisma of visionary leaders (Walsh and Ham, 1997), who have successfully changed this vision into reality (McCormack et al, 1999). It has long been accepted that the nurse–patient relationship is viewed as central to the practice of nursing (Peplau, 1952; Benner and Wrubel, 1989). The aim of this review is to examine the literature on the role of the CNS. It will focus at the outset on the role of the CNS and subsequently in Palliative Care working in the community.

The methods used to compile this literature review included initial references which were known prior to commencing the project and the use of bibliographies in these references. A number of electronic databases were searched. A final search was conducted in December 2014. These electronic databases included PubMed, Biosis Previews, the Cochrane Library, Web of Science and the Web of Knowledge as well as the generic search engine “GoogleScholar” (www.google scholar.com). These were all chosen, being online databases for health. The literature was explored to identify what was already known about this area. The concepts and theories relevant to the area, the research

methods and strategies previously employed, and controversies which had emerged in the workplace from a local, national and international perspective were all considered. Inconsistencies in the findings and unanswered research questions relating to the area were identified. Having explored the literature and identified the gaps, the need for further research in this area will be demonstrated.

The search covered all years from 1990 as the CNS role in Palliative Care is a relatively recent development. Key words included Clinical Nurse Specialist, Palliative Care, Role and Community. In addition local libraries were contacted as were the Irish Cancer Society (ICS), IHF and the Irish Association for Palliative Care (IAPC) and Education Departments. This was in an effort to determine if unpublished research studies had been conducted relating to the key words. There is a wealth of literature pertaining to the CNS in general and to their clinical role. Albeit that there has been research conducted internationally relating to the role of the CNS in palliative care, there is a lack of research in Ireland specific to this topic and more particularly to the impact of the role in the community.

Having identified the literature, it was then necessary to consider a systematic mechanism to review this work. This analysis was conducted through a critical appraisal of the literature where an overall impression of the quality of the research articles was investigated and used to evaluate and assess the information. The purpose of the critical appraisal was to assist in the development of reasoning for the potential quality and contribution of the research under review (Long and Godfrey, 2004).

There has been a range of critical evaluation tools developed in recent years e.g. Hewitt (2007a) and Long and Godfrey (2004). These were considered but the Critical Appraisal Skills Programme (CASP) Qualitative Research and Systematic Review Checklist (www.casp-uk.net) was deemed to be most appropriate because of its succinct nature and its coverage of all elements of the research process.

As referred to in the first paragraph of this section the themes that emerged from the review will now be presented. These include CNS Role Development, Organisational Impact of Role, Theoretical Framework of Role Theory, CNS Role Development in Palliative Care, Organisational Impact of the Role of the CNS in Palliative Care, Perception of Roles and Challenges encountered. The theme CNS Role Development will now be presented.

2.1 CNS Role Development

The role of the CNS has seen rapid development in recent years, though the original idea is over 100 years old (Trevatt and Leary, 2010). The emergence of the CNS can be traced back to North America during the 1940s (Hamric and Spross, 1989). In the 1940s, Peplau (1965) characterised the notion of a specialist in clinical nursing with the evolution of the CNS in psychiatry. Following World War II, nurse educators developed the concept of a CNS as a mechanism to reform the depersonalised patient care system (Montemuro, 1987). These nurse educators had a vision that the CNS would bring expertise to the bedside role, as well as providing an opportunity of advancement for nurses who wished to remain in direct patient care (Dunn, 1997).

In the UK the title of CNS arrived at a much later time during the early 1970s (Hunt, 1999). The increase in specialist nurses in the UK was attributed by Castledine (1994) to nurses' increased knowledge and skills, with an ambition for a more diverse career structure. By 1983, encouragement from the Royal College of Nursing (RCN) led to some centres of excellence such as the Royal Marsden Hospital employing CNSs (Raja-Jones, 2002). In the next decade, nurse practitioner and CNS posts continued to proliferate. This growth was further encouraged by the decision to reduce junior doctors' hours (Department of Health, 1991; National Health Service Management Executive, 1991) and by the introduction of the UKCC Framework on the Scope of Professional Practice (1992).

Many decades following the development of the CNS in North America (Peplau, 1965), the Report of the Commission on Nursing in Ireland (Government of Ireland, 1998) recommended the development of a clinical career pathway for clinical nurse specialism. To support the creation of specialist posts with clear frameworks for approval, the NCNM was established in 1999 (NCNM, 2008). In an effort to explore thoroughly CNS role development, the components of the role, educational requirements, and the concept of clinical expertise will be reviewed.

2.1.1 Components of the CNS role

There has been much debate relating to the components of the role of the CNS. It was envisaged in the USA (Hamric and Spross, 1983; 1989) that the CNS role was to improve patient care through direct practice, role modelling and education of others. To achieve this, the American Nurses Association (ANA) (1980) identified primary criteria for CNS education, certification and clinical focus. In addition, Hamric (1989) highlighted sub-roles

for the CNS of expert practice, education, consultation and research together with a range of competencies. More recently the National Association of CNSs in the USA advanced the competencies and outcomes through a conceptual model of CNS practice (Lewandowski and Adamle, 2009). Three spheres of CNS influence have been introduced, the patient sphere, the nurse and nursing practice sphere and the organisation sphere.

By 1994 the UKCC defined the core nature of nursing and the conceptualisation of specialist nursing. In 2001, the UKCC identified the standards for special education and practice, where specialist practice required higher levels of judgement, discretion and decision making. These focused on four broad areas of clinical practice, care and programme management, clinical practice development and clinical practice leadership (UKCC, 2001). In Ireland, the NCNM (2008) specified the educational qualifications, the experience required and the core competencies of clinical practice, patient advocacy, education and training, research, audit and consultation for the CNS. Elliott et al (2012) suggested that the development of advanced practice in Ireland occurred in a planned and systematic manner with roles being differentiated as either clinical specialist or advanced practitioner roles.

2.1.2 Educational Requirements of the CNS Role

The debate on role has been followed by the debate on educational requirements, owing to the perceived need and consensus for the educational preparation of the CNS (Synder, 1989). In the USA in 1965, the ANA position paper stated the title of CNS could only be used by nurses with a master's degree in nursing (ANA, 1976). By 1997, the RCN in the UK, attempted to address this issue and considered that a specialist nurse should be educated to first-degree level, having studied a series of core modules (Raja-Jones, 2002). In Ireland, the NCNM (2008) recognised the importance of education by indicating that the nurse should have undertaken post-registration education in the area of specialist practice at level 8 or above on the National Framework of Qualifications in Ireland (www.qqi.ie). When the role was originally introduced in Ireland in 2001, it was accessible via an immediate pathway where the candidate had to provide evidence of working in the specialist area for a period of five years.

2.1.3 Concept of Clinical Expertise

The CNS is recognised worldwide as having expertise in a given field, which they use to develop the practice of others (Austin et al, 2006). Hurlimann et al (2001) advocated that being an expert means having a wide scope of clinical competence and theoretical knowledge. Experts are viewed by Graham et al (2006) as working at a higher level of practice, and in complex environments. Martin (1999) proposed that personal qualities such as being supportive, persuasive, accepting, tolerant and questioning, and inspiring confidence reflects an expert. These attributes together with the higher level of practice identified by Graham et al (2006) differentiate the CNS from the Registered General Nurse (RGN). Particular characteristics that separated the CNS from the RGN identified in Glen & Waddington's (1998) study on the role transition from staff nurse to CNS were the ability to practice autonomously and having job discretion. Though data was collected over a year long period in this case study, through a number of data collection methods only two CNSs participated in this study. Both CNS' had only been in post for one year. Although it was not clear how these particular CNS' were selected, both developed personally and professionally during the year's study and were found to have demonstrated innovation in the role of CNS (Glen and Waddington, 1998). This time span could also be attributed to the progression from novice to expert as identified by Benner (1984).

Benner et al (1996) and Decker (2006) suggested that expertise is gained in practice where there is ample experience in the clinical setting. This is attributed to the nurse's shift from dependence on abstract principles to the application of concrete experience where clinical situations are viewed within context and as a whole. However, Benner's work has come under criticism as Husband (2008) argued that it is unrealistic to expect a CNS to be an expert in all the dimensions of the role. In addition to being an expert Benner (1984) suggested an intuitive judgement was also required. It is this intuition that Paley (1996) proposes determines expert ability and is supported by English (1993). Darbyshire (1994) refuted that intuition is not the prerogative of experts. When expanding on the term expert, Benner (1984) purported that it was not the individual who was the expert, but the knowledge and practice within a specific context that was considered expert. Four fundamental patterns of knowing in nursing were identified by Carper (1978) as empirics, esthetics, and the components of both personal and moral knowledge. "Knowing the patient" was central to the nurses' clinical judgement and described in daily rhetoric (Tanner, 2006). Carper's (1978) science and art of knowing in nursing together with the personal and moral knowledge, corroborated with Benner's (1984) knowledge,

practice and intuition of the expert. When discussing specialism in nursing, Wickham (2003) emphasised the importance of distinguishing between the CNS and specialist nurses. This point is highlighted by Maclaine (1998) who recognises the clear difference between working within a speciality and being a nurse specialist. Harris and Redshaw (1998) echoed this, noting that the skills required in some specialist areas, for example critical care, could not be equated to the demands made on nurses who worked in pioneering specialist roles (Wickham, 2003). Bousefield (1997) advised that a successful CNS was one who maintained patient care as a primary focus.

Many benefits have been attributed to the CNS as the role has developed. The Canadian Nurses Association (CNA) (2008) identified that the CNS possessed the education, clinical expertise, decision making, leadership skills, and understanding of organisations. Jones (2005) and Por (2008) recognised that defined roles and responsibilities permitted efficient and effective practice that could be measured against skills, knowledge and qualifications. Though the CNS had the skills, expertise and education, confusion persisted regarding role clarification and regulation in New Zealand (Roberts et al, 2011), Australia (Lowe et al, 2012), Canada (Donald et al, 2010) and the UK (Jones, 2005; Brook and Rushforth, 2011).

2.2 Organisational Impact of the Role

The basic steps in facilitating the introduction of a CNS role within an organisation were described by Baird and Prouty (1989) as involving and guiding the nursing staff. This included enhancing networks with other institutions. Organisational structures, functional operations and evaluation (Baird and Prouty, 1989) can foster the CNS role. This is ever more important with the increasing demand on the cost effectiveness of services. Organisational theorists argued that the effectiveness of any enterprise is determined significantly by its culture, values, patterns of communication and the propensity for collaboration (Parker, 2000). Furthermore, Opie (1997) suggested while there are considerable benefits to teamwork, these could be offset by the inadequacy of organisational support together with unclear structures and directions.

The CNA (2008) suggested that the CNS had the ability to identify, initiate change and work through problems and challenges, where solutions were found which enhanced the provision of timely, accessible, and high-quality care for all patients. However, for the CNS to facilitate practice outcomes and have the desired impact on practice experience, Jeffreys (2005) contended that the complex skills of collaboration and consultation were

paramount. Jokiniemi et al (2012) undertook a systematic review of advanced nursing roles of the nurse consultant, the CNS and clinical nurse consultant (CNC). Results of this review indicated where the advanced nursing roles were supported, developed carefully and evaluated regularly, that this facilitated a positive impact on patients (Coster et al, 2006), nursing as a profession (Coster et al, 2006; Wolf and Robinson-Smith, 2007), provision of care (Coster et al, 2006; Mayo et al, 2010), and the organisation (McFadden and Miller, 1994). However, Jokiniemi et al (2012) argued that organisational, resource, interaction, and role challenges were not mutually exclusive, and influenced each other. This systematic review determined that the implementation of the advanced nursing role would be impeded without the application of procedures (Jokiniemi et al, 2012). Even though this systematic review captured literature from three different countries of the UK, USA and Australia, there were varying advanced nursing titles used in each of the countries. Of the 589 articles filtered, only 40 were selected to be reviewed and these included a combination of qualitative, quantitative and combination methods.

Transferability of findings is concerning as some studies of advanced nursing roles in Australia were not included because of varying titles. Therefore studies of importance may not have been included. In addition, the CNC role in Australia had a lower level of education and so the review was not comparing the same type of advanced nursing role.

Invariably, a coherent evidence base is required to demonstrate the impact that CNS' have at the clinical "coal face", particularly in these times of increasing patient demand, the ageing demographic, reduced finances and organisational change. The organisational impact of the role will examine teamwork, culture, leadership and communication and its influence on the role of CNS.

2.2.1 Teamwork

Freeman et al (2000) used a case study approach to explore the factors which inhibited or supported collaborative practice in their research study to explore the impact of individual philosophies of teamwork on multi-professional practice. Six teams representing acute, community and covering both were selected from a number of specialisms with a wide range of professionals. It was not clear how any of the teams were selected apart from one team being selected because of its national prominence for its supposed total integration of professional input to care. This suggests that the other teams were not totally integrated. A period of three months was spent with each team, where data was collected through extensive observation and interviews with members of each profession within the team. Findings of this study suggested that a shared team culture, open

communication, mutual respect between practitioners and MDT discussions were assigned equal importance for effective team working. The expertise of the CNS was considered essential by Vidall et al (2011) to the functioning of the MDT. Effective liaison between the professionals involved in patient care and continuity along the care pathway were mechanisms identified for the CNS to achieve this (Vidall et al, 2011).

With a case study methodology Elliott et al (2012) participated in a national evaluation of the impact of specialist and advanced nursing roles in Ireland. This purposive sample of twenty three practitioners of CNS and Advanced Nurse Practitioners (ANP) was chosen from a total population of 2101 practitioners (NCNM, 2008). It is unclear how the NCNM, who held the database, aided the identification of potential participants. Seventeen CNS' participated in the case study, crossing twenty eight health service provider sites, both acute hospitals and community settings across the country and with representation from all nursing disciplines. Palliative Care Nursing was captured within the general nursing register of the NCNM. Six CNS' participated in this case study representing general nursing. The methods used included non participant observation, interviews and on-site written records. Findings indicated that both the CNS and ANP were recognised within the MDT for their clinical expertise in the area of specialist practice. This was decided to be central to coordinating patient care and communication in the MDT, the patient, family, and primary care team (Elliott et al, 2012). Because of the small number of CNS participants in this study, it is difficult to determine that these findings are generalisable to the total CNS population in the Irish setting.

One of the clinical competencies that emanated from Nieminen et al (2011) qualitative study of CNSs in paediatrics, internal medicine, surgical units and advanced practice nurse students was multi-professional teamwork. Twenty six CNS' in Finland, from the three different specialities within a hospital were selected by their nurse managers in accordance with previously agreed criteria together with eight Advanced Practice Nursing (APN) students. The criteria included nurse-led outpatient clinic, competence, expert knowledge and special responsibility tasks. Focus group interviews were the only method of data collection used in this descriptive, qualitative study. As the skill sets of the APN students were different to the CNS skills, this impacted on the credibility of the study. Mutual professional exchange and the support of physicians were deemed important to enhance teamwork. Competence was believed to be reinforced through cooperation and collaboration within the interdisciplinary team (Nieminen et al, 2011).

The potential for conflict was signalled by Glen and Waddington in 1998 between the individual CNS goals, targets and those of the MDT within the organisation. This case study referred to earlier examined role transition from staff nurse to CNS and attributed the potential for conflict to team and organisational factors. The need for role clarity, support and supervision was recognised by Glen and Waddington (1998). More recently, hospital cancer nurse specialists in Willard and Luker's (2007) grounded theory study employed several strategies to implement their role when working within the team. A total of twenty nine cancer nurse specialists from five hospitals with cancer services and five district general hospitals participated in this study. All cancer nurse specialists were forwarded information about the study and invited to attend. This study was conducted over eighteen months where twelve cancer nurse specialists agreed to be observed, fourteen consented to be interviewed and three consented to both. Rigour was achieved for this qualitative research when the emerging theory was discussed with the participants and subsequently with other specialist nurses. Difficulties of acceptance were encountered from doctors, in addition to insufficient organisational support for their role. These difficulties impacted on the nurse's ability to provide supportive care to cancer patients (Willard and Luker, 2007). Jokiniemi et al (2012) systematic review, referred to earlier, highlighted that lack of support combined with high expectations and difficulties within working relationships in the MDT had the potential to undermine advanced nursing roles.

Robinson and Cottrell (2005) sought to investigate the perspectives and experiences of health professionals on the impact of multi-agency teamwork, on their professional knowledge and ways of working. This qualitative, multi-method study, focused on how professionals worked, communicated and learned together. This study consisted of three phases with no detail of the timeframe involved. Phase one comprised of observations of team meetings together with analysis of documentary evidence. The selection criteria for the multi agency teams involved were not presented. Phase two and three included interviews and focus groups with the team members. In addition, the types of professionals involved in the teams were not identified impacting on the reliability of the study'. Multi-agency teamwork was found to blur professional knowledge, boundaries and challenged professional identity as roles and responsibilities changed (Robinson and Cottrell, 2005).

Elliott et al (2012) findings indicated that the CNS was recognised for clinical expertise in the MDT while Nieminen et al (2011) suggested that professional support, cooperation and collaboration enhanced teamwork. However, for the CNS whose role is embedded in

multidisciplinary and multi-agency teamwork, the actual and potential conflicts concerning models of understanding, roles, identities, information sharing and links with other agencies are concerning.

2.2.2 Culture

Leininger's theory of cultural care diversity, universality and her illustrative sunrise model (Leininger, 1991; 1994; 2002) can provide a valuable resource and guide to CNS role development with culturally diverse populations. Jeffreys (2005) suggested the desired outcome of the model is cultural congruent nursing care. Leininger defined cultural congruent nursing care as "those cognitively based assistive, supportive, facilitative, or enabling acts or decisions that are tailor-made to fit with an individual's, group's, or institution's cultural values, beliefs, and lifeways in order to provide meaningful, beneficial, and satisfying health care, or well-being services" (Leininger, 1991:49). Cultural congruent nursing care involved the systematic assessment of the dynamic patterns and cultural dimensions of a particular culture. This included religious, social, political, economic, educational, technologic, and cultural values. It considered how these factors may be interrelated and function to influence behaviour in various environmental contexts.

The key to promoting cultural congruent care required nurses to be self-reflective about their own culture. Jeffreys (2005) inferred that nursing can be recognised as a unique subculture that shared some values, beliefs, and practices with other health care professionals. As a culture broker, the CNS actively strove to connect gaps and mediated and as Jezewski (1995) indicated, this reduced conflict and produced change.

The CNS, along with all nursing, has to be culturally aware and become sensitive to other cultural groups through self awareness of their own personal biases and reflect on how these biases may influence perceptions of culturally different populations (Jeffreys, 2005). The role transition from staff nurse to CNS was negatively affected by cultural factors in Glen and Waddington's (1998) case study. Jeffreys (2005) recognised that the CNS of the present and of the future needs to be an active participant in the process of achieving cultural competency. In addition, she signified the need for a repertoire of strategies through continual skill acquisition and refinement towards meeting this goal (Jeffreys, 2005).

2.2.3 Leadership

Health Workforce Australia (2013) reported that the development of an organisational culture which supports continuous learning and development in leadership is crucial. There was consensus that, as the complexity of healthcare increased, it was vital that nurse experts provided leadership to improve patient care and strengthen healthcare delivery systems (Heitkemper and Bond, 2004). The CNS was ideally positioned to provide such leadership. Meanwhile, in Ireland government policy has included building innovation and leadership competencies for nurses and midwives as part of its strategic plan for healthcare transformation (Health Services Executive (HSE), 2011). The National Cancer Action Team (NCAT) (2010) in the UK acknowledged the contribution of the CNS to lead service redesign, together with implementing practice improvements that responded to changing patient needs. Educating, mentoring, determining measurable outcomes and auditing practice included some of the leadership skills that were demonstrated (NCAT 2010). Aranda and Yates (2009) expected that fundamental to the role of the specialist cancer nurses was the ability to demonstrate effective clinical leadership. Gournic (1989) proposed that clinical leadership was a major component of the CNS role in addition to being an expectation of both management and staff.

Findings of the Elliott et al (2012) study indicated that clinical leadership was demonstrated through a range of means which included guiding and co-ordinating the activities of the multidisciplinary team and acting as a positive role model for autonomous clinical decision-making. In addition, this study also found that professional leadership was not as well developed for the CNS compared with their considerable clinical leadership activities. Elliott et al (2012) accepted that leadership is not specifically identified as part of the CNS specialist role but was embedded in its role description. Policy makers who participated in the study (Begley et al, 2014) identified both the clinical and professional leadership role benefits of the CNS but perceived that the professional leadership role was not as well developed. This is the national evaluation on the impact of specialist and advance nursing roles in Ireland (Elliott et al, 2012) study previously referred to in 2.2.1.

Daly and Carnwell (2003) concurred that nursing leaders were equipped with the knowledge and skill sets to tackle and triage complex health issues. These included critical thinking, creativity, assessment, prioritisation and communication. To be a visionary leader, the CNS has to be a skilled communicator and as perceived in 1998 by the National Association of Clinical Nurse Specialists (NACNS), able to use ethical

reasoning in decision-making, describe reality, and anticipate the future accurately. In many instances, success as a leader is due to a combination of clinical expertise, professional attributes, role clarity, and supportive organisational culture (Elliott et al, 2012). However, where challenges prevail to being a leader in a versatile advanced practice role this can be overwhelming to a sole practitioner. This may be particularly relevant for those new to the role or where mentoring, clinical supervision, or support is insufficient (Elliott et al, 2012).

2.2.4 Communication

A “good bedside manner” has long been realised as significant for health care professionals (Hargie and Dickson, 2004:3). Indeed Nightingale (1860:95) recognised the interpersonal interactions of others which she referred to as “chattering hopes and advices”. As well as conversations involved in the healing process, Nightingale (1860) identified those interactions that had a detrimental effect on the well-being of the patient. Since the Nightingale days, nurses have continued to believe that the interpersonal interaction they have with their patients have the potential to be therapeutic (Jenny and Logan, 1992; Williams and Irurita, 2004). Interpersonal interactions through communication are central to relationships between what a person does and what others do around them (Lambert and Lambert, 1981) by using verbal and non-verbal symbolic acts such as speech, gestures and body language. A key component to effective communication for the CNS in Mulvihill et al (2010) literature review was the use of common language and a shared philosophy. Each day, the CNS and their healthcare colleagues are confronted with challenging situations where effective communication is essential, and at the same time charged with difficulty. The CNS has to ensure that communication linkages have been developed on many levels (Baird and Prouty, 1989). These linkages extend from the patient and family to administration, nursing, medical, other disciplines and outside organisations.

Assertive communication is the means of stating a position with assurance (LaSala and Bjarnason, 2010) and is an impartial, explicit, and relevant means of communication that focuses on solving a problem (Lachman, 2009). The use of assertive communication is imperative for the CNS not only to ensure patient safety and quality, but also when dealing with members of the MDT and management. Wade (1999) indicated that nurses were considered as central figures in MDT communication as they built interdependence and engaged in joint decision making. In a tertiary hospital in the USA, Apker et al (2006) explored through individual and focus group interviews, and observation how CNSs and

staff nurses communicated professionalism in their interactions with members of their health care teams. Four units including surgical and neonatal intensive care, general medical and surgical were the sites in this 348 bed tertiary hospital that this study was conducted in. The criteria for selecting these units was identified as the location where the health care team members interacted most frequently in the delivery of patient care and had a diverse cross section of staff. All staff were written to and invited to participate in the study. Fifty of the 2,848 employees volunteered to participate. These included medical, nursing with three CNS' and clerical staff. Apker et al (2006) identified that the communication skills of collaboration, credibility, compassion and coordination were used by nurses to convey professionalism in health care team interactions. These findings identified a range of communication expectations placed upon CNSs and staff nurses by team members in the current health care system. Of the thirty three nurses who participated, the number of CNSs was small and therefore impacted on the transferability of the findings.

For the CNS to facilitate desired practice outcomes, Jeffreys (2005) suggested that the complex skills of collaboration and consultation are enhanced. Without regular professional communication, a breakdown in clinical practice will develop. Within the current health care system the CNS is required to communicate successfully with members of the MDT and with patients and their families.

2.3 Theoretical Framework

The theoretical approach to be incorporated in this study is role theory. Roles are the dynamic aspect of statuses together with their rights and duties (Stryker, 2006). Biddle (1979) and Burt (1982) used the term role to refer to characteristic behaviours, while (Winship and Mandel, 1983) used it to designate social parts to be played and yet Bates and Harvey, (1975) and Zurcher (1983) offered definitions that focused on scripts for social conduct. Major (2003), and Thomas and Biddle (1966) described the concept of role, particularly relating to role theory as the portrayal of behaviours, characteristics, norms and values of a person or position. Attached to any position are the shared behavioural expectations conventionally called role, while Turner (1962) concurred that behaviour is the product of role-making. Stryker (2006) suggested that the elements entering the construction of roles were dependent on the larger social structures where interactive situations were embedded. As Biddle (1986) suggested many role theorists assumed that expectations were norms, others assumed them to be beliefs while others viewed them as preferences. The result being, that each mode of expectation generated

roles for different reasons, resulting in different versions of role theory depending on the mode of expectation assumed (Biddle, 1986).

Stryker (2006) recognised that roles are expectations attached to positions in networks of relationships resulting in identities being internalised role expectations. However, Biddle (1986) explained role theory by presuming that persons are members of social positions and hold expectations for both their own behaviours and those of other persons where role theory was used to analyse various forms of the social system. An important characteristic of role theory concerns social behaviour. This results in persons behaving in ways that are different but also predictable, depending on their respective social identities and the particular situation under study (Biddle, 1986). Biddle (1986) confirms that many versions of role theory presumed that expectations are the major generators of roles. These expectations are then learned through experience, where persons are aware of the expectations they hold. This infers that according to Biddle (1986) that role theory presumes a thoughtful, socially aware person.

Social structuralism views roles as serving functional prerequisites of the social system, where the relationship between the role and the social structure may change, as the institutions of society evolve (Clifford, 1996) as with the evolvement of the CNS role. Brooks et al (2007) recognised role theory as a conceptual framework that defines how individuals behave in social situations and how these behaviours are perceived by external observers. Role theory joins the emphasis of Sumner's (1906) selection of norms which place demands on members of society to arrive at the conception of role. Different norms are assembled into sets of expectations which are applied to specific positions in organised social units, resulting in these expectations defining a role (Stryker, 2006). Accordingly, role theorists use these expectations to build larger and more complex social units in pursuing their interest in issues of social organisation and change. The fundamental referent of the concept of role is the expectations impinging on persons in their interaction with others (Stryker, 2006).

Lambert and Lambert (1981) used the method of Lindsmith and Strauss (1968) to identify four key factors related to interaction, which facilitated role enactment. These included identification of self, behaviour in given situations appropriate to the identification, and background of related acts by others that served as cues to guide specific performance and assessment. This culminated in the evaluation by the individual and others of the role enactment. These criteria identified by Lambert and Lambert (1981) can be used to describe the role of the CNS. This particularly relates to the way the CNS behaves in the

role, the influences of others that guide the CNSs actions and how others view that performance both internally and externally to the organisation (Brooks et al, 2007). Biddle (1986) suggested that roles reflected norms, attitudes, contextual demands, negotiation, and the evolving definition of the situation as understood by the participants. This particularly added insight concerning relationships among roles, role taking, emotions, stress, and the self concept (Biddle, 1986). Redekopp (1997) noted that CNS' commonly articulated role confusion or ambiguity that led to frustration and conflict. Reflecting on the conceptual elements of role theory identifies the professional and personal challenges encountered by the CNS, but also by their nursing colleagues (Brooks et al, 2007).

Role theory has been criticised as promulgating a one-sided view of social behaviour, emphasising consensus, cooperation, and continuity in social life at the expense of disagreement, conflict, and change, and as rationalising the subservience of persons to the social order (Stryker, 2006). However, multiple role involvements can result in intrapersonal, interpersonal, and intra-group conflicts (Stryker, 2006). In addition, Schuler et al (1977) indicated that role theory can also serve as a conceptual framework related to the properties of the organisation and the individual. This premise situates role theory to explore the attitudes and perceptions of individuals, such as health care professionals who interact within organisations to deliver care to patients and families in the local area (Brooks et al, 2007). Role theory is a useful framework to describe role perceptions, providing a means of predicting role stress and allowing for the development of strategies to prevent the occurrence of role strain (Hughes, 2001). As recognised by Brooks et al (2007), role theory is a credible and useful framework to facilitate an understanding of the role perceptions of CNS' in contemporary health care systems. In conclusion, within the current study role theory was a particularly useful framework to explore the role of the CNS in the South of Ireland from the perceptions of patients, families and other health care professionals.

2.4 CNS Role Development in Palliative Care

In the UK, the Macmillan nurse was first introduced in the 1970s with special responsibilities to deliver care directly to terminally ill patients and their families (Nash, 1992). The role of the Macmillan Nurse has changed in the intervening years (Nash, 1990; Webber, 1997). This role is now modelled on that of the CNS in which the clinical consultative, educational, research and supportive functions are combined (Seymour et al, 2002). This correlates with the Irish setting where the Home Care Nurse was introduced in the 1980's to care for the terminally ill patient (Department of Health and Children,

(DoHC) 2001). The role of the Home Care Nurse included the provision of information, advice and support to patients, families and healthcare professionals in the community. Palliative Care was recognised as a specialist area of nursing practice in the Report of the Commission on Nursing in Ireland (Government of Ireland, 1998). This inherently supported the creation of the post of CNS in palliative care, following the establishment of the NCNM in 1999 (NCNM, 2008). At this time the position of CNSPC was accessible via an immediate pathway where the Home Care Nurse had to provide evidence of working in palliative care for a period of five years.

With an aging population and increasing terminal diagnoses, many government policies promote community-based care of the terminally ill (Brazil et al, 2005). Extensive evidence suggests that well over 50% of people prefer to be cared for and to die at home provided circumstances allow and permit this choice (Gomes et al, 2013; Bell et al, 2009; Higginson and Sen-Gupta, 2000). The National Audit Office in the UK in 2008 reported the figure of 74% of persons wanting to die at home. In Ireland, studies suggest that between 67% (Weafer and Associates, 2004) and 80% (Tiernan et al, 2002) of persons wish to die at home. However, the IHF (2013) in its recent perspective series on Access to Specialist Palliative Care Services and Place of Death in Ireland indicated that only 26% of people actually die at home. Coupled with this is the expanding provision of palliative care services to patients with a non-malignant as well as malignant disease (Fisher, 2006; Yang et al, 2012). The National Institute for Health and Care Excellence, (NICE) (2004) recommended that Community Specialist Palliative Care Nurses (CSPCNs) have the expertise to facilitate and provide intensive, coordinated support to patients with complex needs who wish to stay at home. Invariably these changes in society and service provision have realised the importance of the CNS in palliative care. Dark et al (2011) suggested that the workload of the CNS in palliative care was perceived to be considerable and appeared to have increased in recent years. Dunlop & Hockley (1998) argued that regardless of the composition of the palliative care team, one of the key members is the CNS. This was supported by the recommendations of the Calman-Hine report (Calman and Hine, 1995) and subsequent publication by the Cancer Collaboration of the Workforce and Training Implication for Cancer Care (Department of Health, 2000) which stressed the need for more CNSs.

Seymour et al (2002) study formed part of a large evaluation study of twelve Macmillan nursing services in both the community and hospital setting in the UK (Skilbeck et al, 2002). Through semi-structured interviews with forty four Macmillan Nurses and forty seven key colleagues including nurse managers, consultant, NHS managers and others,

Seymour et al (2002) focused specifically on issues for the Macmillan Nurse role. Although interview guides had been developed the interviews were conducted by four researchers in one region and two different researchers in a second region. Because the interviews were conducted by two lots of different researchers, this had the potential to influence the interviews and the resultant findings. The different researchers could affect the direction of the interviews and had the potential to impact on the reliability of the findings. In an effort to address this one of the researchers cross compared all twelve case study reports and all individual interviews where core themes were identified. However, Seymour et al reflected in 2002, as part of their findings and in order to ensure the expertise of the CNS in palliative care was used efficiently and effectively, that there was an urgent need to clarify the nature and scope of the Macmillan Nurse role. Similarly, Husband and Kennedy (2006) contended that there was a wealth of descriptive literature pertaining to the CNS in general and specifically to their clinical role but there was a dearth of research specific to the role of the CNS in palliative care. With this in mind the CNS role development of palliative care will consider the organisational impact of the role and its influence on teamwork, culture, leadership and communication.

2.5 Organisational Impact of the Role of the CNS in Palliative Care

Gomes et al (2013) conducted a systematic review on behalf of the Cochrane Collaboration where they evaluated the impact of home palliative care services on outcomes for adults with advanced illness and their family caregivers. The setting for these studies included Canada, Italy, Norway, Sweden, UK and the United States. This systematic review (Gomes et al, 2013) included a total of 23 studies including 37,561 patients and 4042 family caregivers and results provided clear and reliable evidence that home palliative care increased the chance for patients to die at home with a reduction in symptom burden. This was particularly so for patients with cancer and Gomes et al (2013) suggested that this justified the provision of home palliative care for patients who wished to die at home. Home palliative care services were found not to increase grief for family caregivers after the patient died (Gomes et al, 2013). A limitation of this systematic review related to the lack of consistency in terminology concerning "usual care". This is particularly relevant when considering models of care across a number of countries.

Many of the Macmillan nurses in the Seymour et al (2002) evaluation of UK Macmillan Nursing in the twelve sites were found to lack the resources, organisational infrastructure, managerial support and collegial mentorship to ensure that the benefits of palliative care was available to a large number of patients. Additionally, in the same evaluation study

variances were observed by Skilbeck et al (2002) across hospital and community settings of patient's problems and needs where Macmillan nurses were involved in the delivery of care. Though Skilbeck et al (2012) recognised that randomised controlled trial (RCT) was the preferred design for an evaluation study because the intervention was restricted to one known group, an RCT was not feasible. This evaluation study was therefore a prospective, longitudinal and comparative case study using a combination of quantitative and qualitative data collection methods. All of the thirteen teams were approached across the hospital and community and twelve agreed to participate in this study. Seven of these teams were in the hospital, four in the community and one an integrated team between the hospital and community. From an organisational context, findings reported that patients in the community were less likely to receive face to face visits (Skilbeck et al, 2002). However, Skilbeck et al (2002) suggested that visits, interventions and care were managed depending on patients' problems and needs.

A coherent evidence base is needed to demonstrate the impact of the CNS in palliative care in the South of Ireland at the clinical "coal face", particularly in these times of increasing patient demand, the ageing demographic, reduced finances and organisational change. The organisational impact of the role will now examine teamwork, culture, leadership and communication and its influence on the role of CNS in palliative care. Although there were twelve teams, the number of community based teams was small and impacts on the transferability of the findings. However, a triangulation of methods was used to form the themes in the study and enhance the validity of the findings (Creswell and Miller, 2000).

2.5.1 Teamwork

The concept of teamwork in palliative care is vital (Prouse, 1994). It is particularly vital from the clinical perspective for the multi-professional team, but also for the wider hospice team (Barker, 2000). This is most relevant for the palliative care patient with fluctuating health needs when care may be required throughout the disease trajectory. Bliss et al (2000) literature review of the inter-professional working in palliative care in the community acknowledged the importance of the provision of a quality and effective palliative care service in the community. This was particularly crucial as Higginson (1993) stated that four-fifths of people receiving palliative care spend the majority of their final year of life at home. Seale & Cartwright (1994) and Field (1996) supported this by reporting that while the minority of deaths occur at home, the place of care leading up to death is in the home. Bliss et al (2000) suggested that challenges were encountered in

inter-professional working in palliative care. Understanding of roles and acknowledging professional values were highlighted as significant. Shared planning and decision-making, shared responsibility and non-hierarchical relationships were identified as being necessary for effective collaboration in a concept analysis conducted by Henneman et al (1995). This was particularly relevant in the Irish setting as the professionals working with the CNSPC in the community all have different roles and attributes to bring to patient care and each needs to be acknowledged and valued.

2.5.2 Culture

Jones (2005) confirmed the importance of organisational culture in a systematic review and meta-synthesis on role development and effective practice in specialist and advanced practice roles in acute hospital settings. For the practitioner who had transferred from staff nurse to CNS, organisational culture limited the extent of role transition, when Woods (1999) examined the issues faced by advanced nurse practitioners in the UK as they attempted to implement a new role in practice. A qualitative enquiry using a descriptive exploratory approach on the learning, development and support needs of the CPCNS was undertaken in Northern Ireland by Whittaker et al (2014). The findings indicated that the organisational culture influenced the learning, development and support needs of the CPCNS in fulfilling all aspects of their role. The organisational culture was found to have a significant effect on how the CNS practiced and was interpreted (Whittaker et al, 2014). This signifies that depending on the value, support mechanisms, working relationship, and organisational culture of each organisation, that this has an impact on the CNS in Palliative Care.

2.5.3 Leadership

A descriptive study of nurse-patient interactions was conducted by Howell et al (2014) in the north of England. Four CNS' participated in this study and the small number impacts on the generalisability of the study. The aim was to describe the Community Palliative Care Clinical Nurse Specialist (CPCNS) activities during interactions with patients. This qualitative approach used observation and audio recording of interactions over a period of weeks. Permission was received from the York NHS Research Governance and Research Ethics Committee to conduct a service evaluation. Observations were recorded involving thirty four patient episodes. However, the details concerning the patient consent and ethical procedures are not detailed. One of the themes that emerged from these findings was leadership and coordinating care. Examples of this were

identified by Howell et al (2014) as overall coordination of the care package, liaising with others, referral to others and contact between primary, secondary and tertiary care and other agencies.

In a Canadian study, Stilos and Daines (2013) explored the leadership role of the CNS in an Inpatient Palliative Care team. In the past there had been confusion and inconsistency in the delivery of care. Stilos and Daines (2003) found that there was a clear and transparent process to manage the competing needs of patients referred for care as the CNS had a clinical leadership role as triage leader.

2.5.4 Communication

Without regular professional communication, a breakdown in clinical practice will develop. The need for effective communication skills has been highlighted in a number of studies involving the CNS in Palliative Care. Using semi structured and focus group interviews, Street and Blackford's (2001) critical study in Australia examined the communication patterns between palliative care nurses in the community, hospice and hospital and GP. This qualitative study sought to examine the communication issues for the interdisciplinary community palliative care team. However, nurses were the only discipline included in the study. The findings indicated a number of issues which impeded effective communication including networking, multiple service providers and lack of standardised documentation. Successful networking was contingent upon health professionals understanding each other's roles and expertise. More recent studies have demonstrated concerns regarding communication and the CNS in Palliative Care. Lewis and Anthony (2007) conducted a patient and family survey in a community CNS service. Communication with the primary health care team and between the CNS and hospital doctors was relatively poorly evaluated by patients and families (Lewis & Anthony, 2007).

Through qualitative methodology Tunnah et al (2012) aimed to explore the feelings and experiences of hospice at home nurses providing palliative nursing care to patients in the community in Wales. The team comprised of ten nurses all of who were asked to participate in semi-structured interviews. Though there was no obligation to participate it was unclear how many nurses participated in the study in this small team. The interviews were conducted by the project manager who had both management and research experience. Though known to the nurses, the project manager did not have a clinical relationship with the nursing team members. This can have both positive and negative effects where the interviewee may feel less threatened by someone known to them or

alternatively they may feel inhibited being interviewed by someone known to them. Tunnah et al (2012) study on stress in hospice at home nurses identified difficulty communicating with the GPs and district nurses. The issues concerning communications and its impact have been further confirmed by Gallagher's (2013) study on the development of a seven day Community Specialist Palliative Care Service. Participants who included district nurses identified issues concerning communication, either between themselves and other health professionals or with patients (Gallagher, 2013).

Mulvihill et al (2010) undertook a literature review to obtain an improved understanding of the role of the specialist palliative care community nurse. Communication and collaboration emerged as one of the themes from the literature review. Hamilton and McDowell (2004) conducted a qualitative study to ascertain the influences on the role of the nurse providing palliative care. This qualitative exploratory study undertaken in Scotland used a convenience sample of two rural community hospitals from a total of five with one to two beds designated for palliative care. Purposive sampling was used to recruit the nursing and medical staff within the two hospital settings. As a result of the inclusion and exclusion criteria, only four of fourteen nurses and two of eleven doctors were eligible to participate in semi-structured interviews in this study. Limitations of this study include the local population of 50,000, and the small sample size. Their findings indicated that without open channels of communication, professional and personal barriers emerged among the multidisciplinary team (Hamilton and McDonnell, 2004). Mulvihill et al (2010) recognised that effective communication enhanced the smooth transition between services, continuity of care, and avoidance of duplication.

Effective communication, mutual respect and the acknowledgment of the professional expertise, talents and beliefs of individual team members is essential to team functioning (Turner, 2011). This raises the issue and requirement of the need for good communication between all health professionals, not just between the district nurses and specialist palliative care services (Gallagher, 2013). According to the literature review conducted by Rose and Glass (2006) communication that encompassed empathy, self-awareness, reflective practice, sensitivity and compassion led to nurse satisfaction and better patient relationships.

2.6 Perception of Roles

Understanding role perceptions and interactions assisted in describing models of care. Additionally this assisted in the advancement of professional issues and resulted in

decreasing role conflict and role burden (Brooks et al, 2007). In 2000, Bamford & Gibson explored the role perceptions of practicing CNSs. The study was conducted in two acute hospitals and the role was determined to have a clinical focus, involvement in education and training, acting as a consultant and participating in or undertaking research, along with administrative tasks and liaison. Hamric in 1989 inferred that the expectation that continued refinement of role definition and expression leads to improved specialist practice and advancement of the profession.

More recently there has been a focus on patient and carers experiences of CNSPC. Mitchell (2010) conducted a literature search to identify aspects of care that were deemed invaluable to patients and their families. This was most important as patient perceptions differ to carers but additionally it contributed to service development. The most important element of care was the provision of emotional support and expertise in the management of symptoms (Mitchell, 2010). The patient as recipient was central to the provision of the palliative care service. Their understanding of the CNSPC can help in the future delivery of services. Chapple et al (2006) conducted a qualitative study of narrative interviews with 25 patients concerning the work of the specialist palliative care nurse in twenty one counties in the UK and Wales. Patients who participated in this study had to be well enough to participate in an interview of one to two hour duration so this indicates that patients were well enough to participate and not at the end of life. Patients valued many aspects of the nurses' work particularly their support and information about their condition. In addition, the emotional support and advice on symptoms was helpful. However, patients expressed distress at the early referral to the specialist palliative care nurse. Patients were upset when conversations about place of death were discussed too early. Patients' understanding of the role of the CNSPC is important in the Irish context where this has never been examined.

Common themes have emerged from the literature that related to perceptions of the CNS role in palliative care. These included the CNS as educator, CNS as change agent and CNS as expert practitioner. These will be explored further.

2.6.1 CNS as Educator

The specialist palliative care nurse contributes not only direct clinical care, but also plays an important role in providing education to other primary care providers, such as district nurses, GPs and hospital health-care teams, as well as participating in clinical research

(Mulvihill et al, 2010). This consultancy type of approach is more evident within the community setting (Mulvihill et al, 2010).

For all nurses continuing professional development is essential to ensure that nursing practice is evidence-based, meets best-practice standards and therefore is congruent with the needs of contemporary society (Black and Farmer, 2013). Nursing competence is dependent on the continual updating of skills and knowledge and is an ongoing and career-long process (Cancer Nurses Society Australia, 2013). In the Irish setting, An Bord Altranais (1994) suggested that nursing education must be a continuum, and not something that begins on entry to the nurse training programme and ends at the point of registration as a nurse.

In the Elliott et al (2012) study conducted in Ireland, CNSs and APs were found to take responsibility for guideline development in their own area of specialist practice, implementing new guidelines through dissemination and co-ordinating reviews. Additionally, they were recognised for their clinical expertise, up-to-date knowledge, ability to source information on international best practice, research efficiently and liaise with other specialist practitioners in the region (Elliott et al, 2012). This was in contrast to the findings of Husband and Kennedy (2006) in Scotland who explored the role of community nurse specialists in palliative care as educators where CNSs were expected to contribute to the delivery of education but many had received no formal training to support them in this aspect of their role. Participants in this study were drawn from four teams of CNSs (Husband and Kennedy, 2006). Fifteen CNS' in the four teams were contacted, eleven of whom volunteered. However, the overall numbers were small as eight CNSs were randomly selected for interview and two participated from each team. This resulted in the CNSs in Husband and Kennedy (2006) study avoiding this aspect of their role. Nurses were concerned about their credibility as a teacher and their ability to transfer information. Similar findings were reported by Seymour et al (2002) who identified that delivery of education was an integral part of the role but issues were acknowledged as many CNSs had not received formal training in the area.

The CNS post-holders emphasised their important educational role in Jack et al (2003) study conducted in the acute hospital. They all identified the educational input as being part of giving the staff skills to empower them to care for palliative care patients and their families (Jack et al, 2003). The stakeholders, who held the more senior posts, identified the importance of the education of clinical staff as being an integral part of the CNSs role (Jack et al, 2003). Howe et al (2000) suggested an additional obstacle for community

nurses as educators is the historical hierarchical relationship between doctors and nurses. While patient education is integral to nursing care, the skills to educate other healthcare professionals may not be readily apparent (Howe et al, 2000).

More recently Stilos and Daines (2013) study on exploring the leadership role of the CNS on an Inpatient Palliative Care Consulting Team recognised that the CNS was able to educate the referring service about palliative care and offer clinical advice when needed by using their judgment and decision making skills. The NCNM conducted an Evaluation of the Effectiveness of the Role of the CNS/ CMS in 2004. This evaluation acknowledged that the educational function of the CNS role was the most important component. However, these findings did not correlate with the data from the questionnaire where 63% rated the clinical aspect of the role as most important while only 20% rated education as the most important. This questionnaire was forwarded to 1,487 CNS' in all care settings and had a response rate of 61%. It was not possible to determine how representative this is of the CNS in Palliative Care as they were included within the general division of NCNM register.

2.6.2 CNS as Change Agent

Change is a regular aspect of the health service. Hurlimann et al (2001) argues that though working in a consultative role means having little opportunity to make decisions. This limits the opportunities of the CNS to contribute effectively to the patient care decision-making process (Hurlimann et al, 2001).

Leading on initiatives for community nurses offers the potential for positive benefits and opportunities to expand and develop their roles (Holt, 2008). In many instances in Corner et al (2003) study exploring nursing outcomes for patients with advanced cancer following intervention, the Macmillan nurses appeared to play a critical role in decisions and actions relating to symptom management. Unfortunately, in their role as change agent it was evident that the Macmillan nurse had little authority to act on their own to alter medication (Corner et al, 2003). Their effectiveness was reliant on their ability to influence the prescribing practices of doctors, though the Macmillan nurse may have had superior knowledge (Corner et al, 2003). Similarly in 2006, Austin et al study of the CNS and the practice of community nurses in the UK, found that specialist services in Tissue Viability Nurses and Continence Advisors had changed over time and that the CNS had 'worked the system' to bring about such change. This ethnographic study, of twenty two CNS's in one health region in the UK was invited to take part in the study. Following purposive

sampling, participant observation visits were conducted with eight CNS'. In addition theoretical sampling was used to select fourteen CNS' for interview. Following data analysis, core categories were identified. Though present, the core categories were not clearly identified in the findings. Austin et al (2006) findings acknowledged that CNS's were the main drivers for service development but they had difficulties introducing new ideas. Any changes CNSs wished to make had to be mediated through their consultants. They lacked authority to bring about change even though they had an advisory role.

In contrast the Hardy et al (2006) project on expertise in practice demonstrated that nurses affected change and facilitated performance and organisational development. This project was undertaken by six groups of CNS', paediatrics to palliative care. The nurses met monthly for twelve to sixteen months at different locations across the UK to discuss how to gather the evidence of their practice expertise. Results of this project indicated that practice expertise acted as a catalyst that promoted positive change resulting in enhanced health care but also that the involvement of a critical companion assisted the CNS in achieving this practice expertise. The CNS'/ CNM'/ APs in Elliott et al (2012) SCAPE study also influenced change where they were active in practice development by a process of initiating formal reviews of clinical practice and patient experiences, identifying specific problems and making changes to patient care and service delivery. They ensured that recommendations from latest research evidence and clinical guidelines were implemented and any changes were introduced into clinical practice (Elliott et al, 2012).

As professional groups navigate processes of change there is a need to explore their roles. Changing practice is linked to concepts of autonomy and authority (Graham et al, 2006). For the CNS to be an initiator of change, they need to be "able to make a difference" (Graham et al, 2006).

2.6.3 CNS as Expert Practitioner

CNSs are recognised worldwide as having expertise in a given field, which they use to develop the practice of others (Austin et al, 2006). Being an expert means having a wide scope of clinical competence and theoretical knowledge (Hurlimann et al, 2001). Benner et al (1996) described that nurses became expert in their practice when they had sufficient experience in the clinical setting to move from reliance on abstract principles to the application of concrete experience. This was demonstrated by viewing clinical situations within their context and as a whole. The expert practitioner who worked at a higher level

of practice, and in complex environments was viewed as “expert” (Graham et al, 2006). For Martin (1999) personal qualities such as being supportive, persuasive, accepting, tolerant and questioning, and inspiring confidence reflected an expert.

The active presence of the CNS was recognised as an essential resource for an effective NHS by Vidall et al (2011). It was anticipated that the presence demonstrated the value of the role and therefore brought specialist knowledge and expertise to ward staff (Vidall et al, 2011). This study was undertaken in an acute hospital.

Variations of excellent and suboptimal practice were found by Clark et al (2002) evaluation study of service delivery of Macmillan nursing services in hospitals and community settings across dimensions of services. This formed part of the evaluation study previously referred to (Seymour et al, 2002; Skilbeck et al, 2002) in 2.5 Organisational Impact of the role of the CNS in Palliative Care. The delivery of palliative care was viewed to be multifaceted and the evaluation included the location and context of the services, the activity levels of the services, the management patterns, work organisation, links with other colleagues and resource use. Clark et al (2002) suggested that from an organisational context, individual skills and health technologies influenced the delivery of palliative care. The CNS demonstrated a broad knowledge base and a wide range of experience in palliative care but it was questionable if the CNSs were equally proficient in all aspects of their role.

2.7 Challenges

Palliative Care has developed from the visionary, charismatic style of the early days to an established entity which now offers a career structure for staff. This is welcomed but also presents its own challenges of managing growth and effectiveness. Expansion invariably attracts increased funding needs which create tensions with opposing values between finance and caring. These challenges have had an impact on the CNS in Palliative Care. Macmillan nurses raised the issue concerning their relationship to palliative medicine in Seymour et al (2002) study. Some services had a long established palliative medicine input while others had been nurse led services. Invariably, advantages were present with greater access to medical advice and support in caring for patients with complex needs. This also provided a mechanism for the CNS to increase their level of specialist knowledge on an ongoing basis. However, fears of medicalisation and an associated less holistic approach to care were reported by Barker in 2000.

The service requirements to enable nurses to care for patients and their families are little discussed and the nature of nursing work, even at the level of the CNS, is poorly articulated (Seymour et al, 2002). It is essential that CNS' gather evidence to show, clearly and robustly, just how important their contribution is to the overall picture of health care (Fletcher, 2011; Smy et al, 2011). Such evidence highlights the pressing need to properly harness and further develop the specialist skills, expertise and quality that CNS' bring to the clinical arena (Vidall et al, 2011). In the NHS, Fletcher (2011) suggests that CNS' need to be able to defend their services through the production of robust business plans demonstrating the benefits of their role in terms of national policy and NHS outcomes.

Capturing the experiences of the other members of the community team is important in understanding their role and perceptions of palliative care services. Oishi & Murtagh (2014) conducted a systematic review of patients, carers and healthcare professional views of the challenges of uncertainty and inter-professional collaboration in palliative care for non-cancer patients in the community. This review included a total of 30 studies and represented the views of 719 patients, 605 carers and over 400 professionals. Studies were predominantly from the UK with a study from the USA, Australia, New Zealand and Sweden. Though the systematic review combined both qualitative and quantitative evidence only three of the studies used a quantitative methodology and three more used mixed methods. The findings of the review were presented through themes. Because the majority of the evidence was from the UK, this presents difficulties in generalising in other locations and cultures unless similar models of care are delivered. The review found that the roles of professionals were unclear to patients, carers and professionals themselves. Barriers identified to effective care were uncertainty of disease trajectory and a lack of collaboration between health-care professionals (Oishi and Murtagh, 2014).

Vidall et al (2011) acknowledged that there were many challenges facing CNS' working within the NHS in the current economic constraints. The NHS is looking to make cost savings and some trusts and senior managers see the CNS role as an unaffordable luxury (Vidall et al, 2011). Role erosion, mergers and cuts are being implemented in a move to recoup staffing costs and reconcile the budgetary deficit (Vidall et al, 2011). This was recognised by Tunnah et al (2012) as an added impact and resulted in conflict because of communication difficulties between the hospice at home nurses and primary care teams and was recognised as a source of stress for the hospice at home nurses (Tunnah et al, 2012).

Similarly, Home Care Nurses (HCNs) in the Stajduhar et al study in 2010 indicated they worked in an under resourced environment, where resources for clients with palliative diagnoses were strained by increases in clients with chronic conditions and high complexity and need in both groups. This two phase ethnographic study in Canada used a purposive sample of twenty nine HCNs in Phase 1 where the nurse completed a brief narrative of four to five decisions made during a patient visit. This nurse subsequently participated in an interview a week later where they had to expand and provide details of the context of their practice. A purposive sample of twenty seven HCNs participated in qualitative interviews to document perceptions of nursing practice in Phase 2 of the study. Though ethnographic, there was no evidence of participant observation or the researchers being immersed in the setting. Stajduhar et al (2010) did argue that interviewing can be considered a form of participant observation. The study was qualitative in nature and the researchers had an interest in the nurse's description of practice and decision making, this was not observed at any time through data collection. HCNs described resource barriers of staffing limitations and restrictions on service and difficulties managing increasingly large workloads (Stajduhar et al, 2010).

2.8 Conclusion

Nursing is not static and continues to grow and develop in Ireland in response to the changing society we live in today (Wickham, 2003). In the Irish setting clear guidelines have been developed (NCNM, 2008) regarding the CNS role and its components. However, the role of the CNS in Palliative Care has not been examined in the South of Ireland. Studies to date have included CNS', varying members of the team and to a lesser degree the patient. In general the results of studies on the CNS role have proven more positive in the hospital setting (Jack et al, 2003; 2004). Difficulties have been encountered for the CNS practicing in the community setting (Husband and Kennedy, 2006; Austin et al, 2006; Clark et al, 2002; Seymour et al, 2002). The impact of the role on the primary care workforce, patient and family and the values on what the role means to the CNSPC is not evaluated in the literature. At this juncture it is imperative to determine the perceptions of the role of the CNS in palliative care in an Irish community setting. Following the process of change from the Home Care Nurse to CNSPC, it is important to have a clear interpretation of what is different now about the role. The nature of the work and the specialist and expert skills need to be understood. In addition, the impact of the CNSPC role and how it has influenced practice on other health care professionals needs to be explored. The patient's perception of the role as recipient of the

service is paramount in understanding the role of the CNSPC. In Ireland, challenges have been experienced no more so than the economic crisis of the recent past.

Historically, caring for the dying patient can be traced back to the Irish Sisters of Charity in the nineteenth century (O'Brien and Clark, 2005). It is important to determine if the perceptions of the role can be related to the development of palliative care in the health service and the Irish culture. Therefore the input of the patient, family, G.P, P.H.N, NCNM and indeed the CNSPC are imperative in this research study.

2.9 Research Question, Aims and Objectives

When I set out to consider my research question, I wanted to understand the role of the CNSPC and I needed to find out about the experience from others perspectives. Therefore, my research question was designed to address my research topic and express the essence of my enquiry. My research question was a means for guiding and focusing my enquiry (Mason, 2002). I then needed to consider the aims and objectives or the purpose of my study. In addition to increasing the intellectual understanding of the role of CNSPC, this was a complex area with the purpose of the study being multi-faceted.

2.9.1 Research Question

The research question which guided this study is

“What is the role of the Community CNS in Palliative Care from the perspective of associated health professionals, patients, and family members in the South of Ireland?”

2.9.2 Aim of Research

The aim of this research is to establish a clear interpretation of the role of the CNSPC in the South of Ireland. The purpose of the research is to achieve insight and understanding of the role from the perspectives held by patients, family members in the home, and health care professionals i.e. the GP and PHN in the South of Ireland and a nurse representative of the NCNM. The perceived role from the CNSPC perspective is examined together with the support measures necessary to deliver the role. The challenges as identified by the CNSPC on delivering the role are explored.

2.9.3 Objectives of Research

The objectives of this research are:

- To critically evaluate the multiple perceived roles of the CNSPC
- To examine the support measures necessary to deliver the role
- To identify the challenges encountered by the CNSPC
- Make recommendations for policy and practice and therefore enabling the CNSPC services to plan for the future

In conclusion, this literature review considered the CNS role development globally and then pertaining to the Irish context. The organisational impact of roles pertaining to literature on teamwork, culture, leadership and communication were examined. Role theory as the theoretical framework pertinent to this study was presented. Specific issues relating to the role of the CNS in palliative care were identified. The evidence relating to the perception of the role of the CNS concerning the CNS as educator, change agent and expert practitioner was evaluated. Challenges encountered by the CNSPC were identified. The final section concluded by illustrating where future research will be focused. The research question, aims and objectives were presented.

The next chapter will present the methodology and methods that examined the role of the CNSPC in the South of Ireland.

Chapter 3 Methodology and Methods

3.0 Introduction.

In this chapter I will discuss the research design which was guided by the philosophical underpinnings of symbolic interactionism (Blumer, 1969; Mead, 1934) and a qualitative approach. This qualitative approach gave meaning and the ability to understand the role and practice of the CNSPC from the perspective of the participants. Through a qualitative approach I will demonstrate how the methods and sampling were employed. Participants were engaged with in their chosen environment in an effort to gather their perspective of the role of the CNSPC through a selection of data collection methods. I will then describe the data analysis of the study. Thematic analysis of the data was used in an attempt to understand the perceptions of the health care professionals, the patients and families (Boyatzis, 1998). This will include the mechanisms used to establish rigor and reflexivity in this study. The techniques used to gather and analyse the data related to the research question 'What is the role of the Community CNS in Palliative Care from the perspective of associated health professionals, patients, and family members in the South of Ireland?'

The aim of research methodology was defined by Kaplan (1964:23) "to describe and analyse these methods, throwing light on their limitations and resources, clarifying their presuppositions and consequences. It helps us to understand, in the broadest possible terms, not the products of scientific inquiry but the process itself". The methodology justifies the methods used in the study while the methods produce knowledge which result in the methodology having epistemic content (Carter and Little, 2007).

3.1 Research Design and Philosophical Basis.

This section will discuss the qualitative research design concerning the ontology and epistemology perspectives of the study. The section will be followed by the philosophical underpinnings of symbolic interactionism and conclude by discussing the qualitative approach which guided this study. I was mindful that the purpose of this study was to gain an in-depth understanding of the participant's perspectives rather than the use of standardised measures where the varying perspectives would be assigned a limited number of predetermined response categories with numbers assigned (Patton, 2002). With this in mind, qualitative methodology was deemed to be in a position to provide the means to pursue a deeper understanding and to explore the different perspectives which would not be available through quantification (Darlaston-Jones, 2007). The "what"

questions of human existence are asked by positivism and quantitative research but these do not provide the detail of in depth understanding posed by the “why” and “how” questions and qualitative research (Darlaston-Jones, 2007). Additionally, as I was located within the social world and natural settings, I was in a position to make sense of and interpret the phenomena under study (Denzin and Lincoln, 2011).

3.1.1 Ontology and Epistemology

From the outset, I required an understanding of the relationship between my view about the nature of reality or ontology (Blackburn, 1993; Bruner, 1990) and the meaning I attributed to epistemology or knowledge and its creation. I recognised this was fundamental in being able to articulate the rationale for the research design and methodology chosen. Blaikie (2000:8) described ontology as “claims and assumptions that are made about the nature of social reality, claims about what exists, what it looks like, what units make it up and how these units interact with each other”. Asif (2013) suggests it is necessary to know what is involved with the nature of reality while Hay (2002:64) asks the question “What’s out there to know?” It was imperative that I reflected upon the nature of reality from within palliative care to determine the research approach (Kramer-Kile, 2012).

With a background in palliative care nursing in the community I had gained considerable knowledge of the area. I was familiar with the CNSPC transition from Home Care Nurse in 2001. However, I was not aware of the difference in practice or how the role had changed for the CNSPC following the transition. In addition I was aware that palliative care nursing in the community was complex. The CNSPC was visiting patients and families in their homes and working with GPs and PHNs but I did not know how these persons perceived the role. Finally, I was not informed of the role difference between the CNSPC and PHN from the patient and family perspective in the South of Ireland.

Skilbeck et al (2002) and Seymour et al (2002) had conducted research on the role of the CNS in Palliative Care in the UK but this had not been conducted in the South of Ireland. Kincheloe et al (2011:170) described the qualitative research process as being ‘ontologically complex’ particularly where “all observers view an object of inquiry from their own vantage points in the web of reality, no portrait of a social phenomenon is ever exactly the same as another”. I see my study as different to both Skilbeck et al (2002) and Seymour et al (2002) because of the difference in location, the culture, the intervening years and the structured development of the CNS role in Ireland. In addition I reflected on

Kincheloe et al (2011: p.170) analogy and recognised the importance of determining the role of the CNSPC in the South of Ireland based on the perspectives of health care professionals, patients and family members.

Five paradigm positions identified by Lincoln et al (2011) were considered when establishing this study. These included positivism, post positivism, critical theories including feminism and race, interpretivist or constructivism and finally participatory and postmodern action frameworks (Lincoln et al, 2011). I reviewed each paradigm and then considered each from an ontological perspective before identifying the research paradigm that was most suitable to my field of study.

Positivism is a paradigm which Grix (2004) described as applying scientific method to personal events which are accepted as belonging to a natural order and open to objective enquiry. From an ontological perspective Guba and Lincoln (2005) identified that positivism believes in a single identifiable reality with a distinct truth that can be measured and studied and this was deemed not to be suitable for the research study.

Denzin and Lincoln (2011) outlined that post positivism relies on multiple methods as a way of capturing as much of reality as possible where emphasis is placed on the discovery and verification of theories. This paradigm was not applicable to the research study because from an ontological viewpoint Guba and Lincoln (2005) suggested that it may not be possible to fully understand this single reality because of the hidden variables and lack of absolutes in nature.

Lincoln et al (2011) referred to the critical theory paradigm as the struggle for equality, social justice, social science and proving the oppression of people. Ontologically, Bernal (2002) recognised that human nature operated in a world that was based on a struggle for power. This ontological paradigm was deemed not to be relevant to the research topic as it dealt with interactions of privilege and oppression based on race or ethnicity, socioeconomic class, gender, mental or physical abilities (Bernal, 2002).

In the fourth, participatory paradigm, Heron and Reason (1997) asserted that it was not possible to have an absolute experiential knowing of what there is. However, in the relation of knowing by acquaintance, the experiential knower shapes perceptually what is there (Heron and Reason, 1997). From an ontological perspective Heshusius (1994) suggests that this post-modern paradigm has a new understanding of the relationship

between self and others with a freedom from objectivity. This worldview based on participative realities by Heron and Reason (1997) was not relevant to the research study.

The final research paradigm reviewed was interpretivism and as detailed by Asif (2013) this paradigm proposes that reality is socially constructed. In this paradigm people actively create their social world and this can be studied in its natural state without manipulation by the researcher (Hammersley and Atkinson, 1983). Guba and Lincoln (1994) assumed from an ontological perspective that reality is constructed inter-subjectively through the meanings and understandings developed socially and experientially. This ontological position of interpretivism suited the research study as I had the means to interact with the participants and therefore I could now ensure that I would create knowledge reflective of their reality. Darlaston-Jones (2007) acknowledged from the interpretivist perspective each participant has a separate and unique reality and each is independent of their interpretation of that reality. I was aware that reality for the participants was different because of their prior experiences, the socialisation process they were subject to, and the resulting cultural differences due to their different positions. Furthermore, there was the reality that each of us has complex reasons for working with palliative care patients and these decisions are influenced by the type of person we are, our experiences of living and dying, culture, background, social, and economic status.

Ontological assumptions lead to an epistemological standpoint (Asif, 2013). Maynard (1994:10) explains the relevance of epistemology where “epistemology is concerned with providing a philosophical grounding for deciding what kinds of knowledge are possible and how we can ensure that they are both adequate and legitimate”. Epistemology asks the question of how reality came to be known and examines the relationship between the knower and known (Vasilachis de Gialdino, 2009). In an effort to uncover my epistemological stance, I considered the question “What is the relationship between the inquirer and the known?” (Lincoln and Guba, 1985:14–15). As researcher I had previously worked with a number of the research participants and so would have been known to them and therefore this had the potential to influence my epistemological stance. However, at the time of data collection I was not working with any of the participants.

The five paradigm positions previously identified were reviewed from an epistemological position. Positivism believes in total objectivity from an epistemological position. Guba and Lincoln (2005) suggest that in positivism that researchers value only the scientific rigour and not its impact on the research participants. This was deemed unsuitable as in positivism there is no interaction with the participants, which was priority for my study. In

post positivism, the epistemological stance deemed that the research and statistics produced provide a mechanism to make a decision using incomplete data (Guba and Lincoln, 2005). Similarly, this was inappropriate as the interaction with the participants was to be kept to a minimum. I did not plan to produce statistics and I expected to have a considerable amount of interaction with the participants.

In the epistemological perspective of critical theories, Merriam (1991) described that researchers believe the knowledge that is produced can change existing oppressive structures and remove oppression through empowerment. This was unsuitable as the study did not aim to find out knowledge concerning oppression. The epistemological stance of the participatory paradigm was deemed to be incorrect for my study, as Heron and Reason (1997) indicated it sets out to understand how we know what we know. This was not the aim of my study.

Finally, I reviewed the epistemological stance of interpretivism and considered this philosophical belief was most appropriate to my study. Guba and Lincoln (1994) suggested that the research and the object of the research are linked, so that who we are and how we understand the world is a central part of how we understand ourselves, the participants and the world. This was of particular importance as I needed to allow the unique differences of the participants to come into focus and simultaneously capture the similarity that united health care professionals who worked with the palliative care patient. Lincoln and Guba (1985) recognised that I as researcher and the participants construct meaning based on our interactions with the surroundings. With my background in palliative care nursing, I wanted the role of the CNSPC to emerge from the study. Of particular interest to me was the knowledge generated from the perspective of all the participants and whether the role was the same or different. In addition I had to be mindful that the meaning and experience may be different for each participant. However, I did welcome the desired outcome being knowledge that changes immediate practice (Mayan, 2010) rather than theory development or general qualitative description (Sandelowski, 2000).

In conclusion, the epistemological position of interpretivism influenced every aspect of the research process I undertook, from the topic selected to the creation of the research questions, to the selection of theoretical lens, method, and overall methodology (Hesse-Biber and Leavy, 2006). Interpretivism and symbolic interactionism share ontological and epistemological assumptions to such an extent that interpretivism meets all of Blumer's (1969) requirements for symbolic interactionism methodology.

3.1.2 Philosophical Underpinnings

Symbolic interactionism was the chosen philosophical stance. This influenced the research design and approach taken to the area of study (Kramer-Kile, 2012). Symbolic interactionism is an approach whose first principle is “that human beings act toward things on the basis of the meanings that these things have for them” (Blumer, 1969:2). In symbolic interactionism the focus is on how we interpret our circumstances and choose one course of action over another. Symbolic interactionism grounds a set of assumptions (Blumer, 1969) that researchers bring to the methodology. The first premise is that human beings act toward things on the basis of the meanings that the things have for them (Blumer, 1969). The second premise is that the meaning of such things is derived from, or arises out of, the social interaction that one has with one’s fellows (Blumer, 1969). The third premise is that these meanings are handled in and modified through an interpretative process used by the person in dealing with the things encountered (Blumer, 1969).

Benzies and Allen (2001) suggested that participants structure the external world by their perceptions and interpretations of what they conceive that world to be. The world exists separate and apart from the participant's perception of it. However, it was the participant's perception of the natural world in which they exist that influenced behaviour (Blumer, 1969). In addition, ideas and behaviours are distinctive processes that are constantly changing depending on how the participant interprets the world. Of particular interest was to know the participant's point of view, together with wanting to understand the processes by which the points of view developed. Blumer (1969) signalled that meanings arose in the process of interaction among participants and finally that meanings were assigned and modified through an interpretive process that is ever changing. The participant and the context in which that participant exists are inseparable (Benzies and Allen, 2001). Therefore, I deemed the focus on interpretation and meaning to be of importance in determining the role of the CNSPC.

As researcher, I recognised my moral responsibility to be sensitive to the lives and circumstances of the participants. This was particularly pertinent to the study area and the lives and circumstances of the patients and family members.

Symbolic interactionism and its epistemological approach favoured a qualitative approach over survey and experimental evidence (Biddle, 1986) and lent itself most appropriately as a methodology to the area of study.

3.1.3 Qualitative Approach

A number of approaches were initially considered for my research question. Initially, hermeneutic phenomenology was considered. The aim of this approach is to describe accurately the lived experiences of people and not to generate theories of the phenomenon being studied (Cohen et al, 2000). I also did not want to generate a theory but I did want to understand the perceptions of the participants, so this was not used. I then considered grounded theory approach, whose purpose is to discover social-psychological processes and generate theory (Strauss and Corbin, 1990). As I did not want to generate theory, this approach was deemed not to be suitable.

I then considered ethnography. The ethnographer's approach was described by Hirsch and Gellner (2001:7) "as a curious kind of cross-eyed vision, one eye roving ceaselessly around the general context, any part of which may suddenly reveal itself to be relevant, the other eye focusing tightly, even obsessively, on the research topic". Savage (2006) suggested that ethnography with its triangulation approach and attention to context is particularly well suited to tackling complexity.

However, I then had to consider the ethical issues associated with this research. This was a small centre and I had confirmed to the participants that their participation in the study would be kept confidential. In ethnography, the researcher immerses themselves in the setting to understand the beliefs and behaviours and describes the culture in detail (Hammersley, 1992). On reflection, I determined that this level of detail and description would be too revealing for my participants and I would not be able to maintain their anonymity as I had indicated in my applications for ethical approval, the consent forms and the information leaflets. I therefore determined that a full ethnography where a rich description of the data collection sites would not be possible due to maintaining confidentiality and anonymity. Therefore to understand the role of the CNSPC and the broader social context which shaped it, a qualitative approach was employed. This qualitative approach was used based on ethnographic principles such that an attempt was made to understand the cultural world of the participants from their own conversations. Similar to ethnography, I did collect data from a number of perspectives but I did not immerse myself in the setting for prolonged periods of time. Neither did I undertake participant observation of the CNSPC undertaking their role as reporting the level and detail of the setting would not have made it possible to ensure the anonymity of the research participants.

I still wanted to ask the questions of “how” and “why” (Fitzpatrick and Boulton, 1994) as I deemed that these were paramount. From a symbolic interactionism perspective, I wanted to know the research participants point of view to try and understand the process through which these developed. A qualitative approach facilitated and provided me with the ability to get into the world of the participants. It allowed me the feasibility within the design to enter the cultural world of the CNSPC, the health care professional, patients and families. This was accomplished through focus group and semi-structured interviews with the participants. Non participant observation was conducted at two team meetings where the observations were recorded in my reflective diary and this was later used in the development of my themes. Through a qualitative approach, I was able to analyse the data so that I could draw out the participant’s understandings and perceptions as well as exploring the features of the social settings and culture (Long and Godfrey, 2004). Therefore, a qualitative approach facilitated the generation of a detailed account of the health care professionals, their relationships, their interactions with patients and families, and their approaches to delivering care, as well as in-depth accounts of patients care experiences.

I had to be cognisant of my professional background and the impact of this on my role as researcher. These challenges are dealt with later in this chapter within 3.12 Reflexivity.

3.2 Methods

The epistemology and ontology identified in the research design directed the choices made in this study. This was in an effort to understand the role of the CNSPC from the perspective of the participants. A qualitative approach commonly uses methodological triangulation and therefore provided a more comprehensive insight in the phenomenon under study. The study of these participants in their naturally occurring settings and by methods of data collection such as non participant observation, semi-structured and focus group interviews and demographic data captured the social meanings and ordinary activities of the participants. Hammersley and Atkinson (1995) considered interviewing as a form of participant observation and this was deemed consistent with the researcher’s interest in the CNSPC descriptions of their practice and decision making. Stajduhar et al (2010) argued that this method was not observable and hence the researcher also conducted non participant observation. A combination of the sites, participants, data collection methods and the themes following analysis are presented in figure 1.

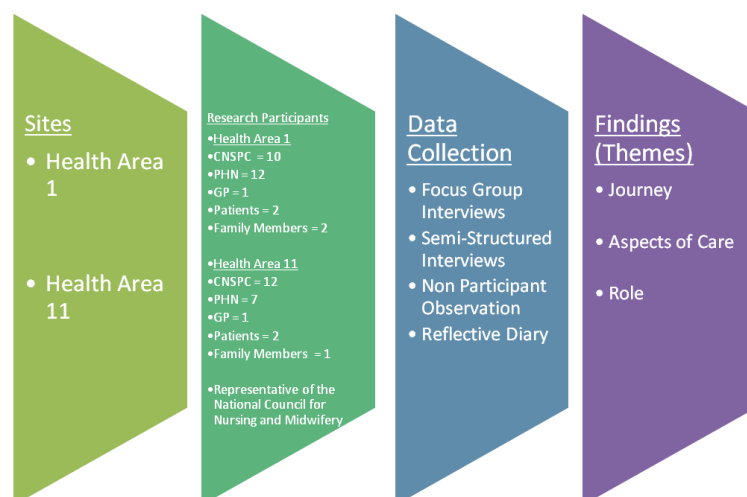


Figure 1: Methods and Findings

There were four phases to this study. Phase one included the recruitment and focus group interviews with the CNSPC. Phase two included the recruitment and semi-structured interviews with the patient and family members. Phase three included the recruitment and focus group interviews with the PHNs. Phase four included the recruitment and semi-structured interviews with GPs and the Representative of the NCNM. My role as an “insider” in the data collection and where I was known to some of the participants is discussed in 3.12 Reflexivity.

Details will now be presented on the interview techniques employed and the non participant observation undertaken in the different settings. The sampling, inclusion and exclusion criteria, recruitment and interview process will be presented. The ethical considerations will be discussed. This will be followed with details on data collection.

3.2.1 Focus Group Interviews

Focus group interviews were conducted with the CNSPC and PHNs. Focus groups were selected because they have been successfully used to highlight the nature of palliative care provision (Hanratty et al, 2002; Barnes et al, 2006; Gott et al, 2009). A particular advantage identified by Denk et al (1997) is that this method allowed access to the informants’ broad “referential structure” whilst simultaneously enabling the expression of contextual details (Gott et al, 2011). Holding focus groups with members of existing health care teams’ further highlighted the cultural values informing the work of the team (Gott et al, 2011).

Powell et al (1996:499) defined a focus group as “a group of individuals selected and assembled by researchers to discuss and comment on, from personal experience, the topic that is the subject of the research”. Focus group research drew upon participants’ attitudes, feelings, beliefs, experiences and reactions. Though focus group interviews could be conducted in a way which would not be feasible using other methods (Gibbs, 1997), social gathering and interaction within the focus groups facilitated the opportunity to reveal attitudes, feelings and beliefs. Focus group interviews were of interest where the culture of particular groups is important, and in exploring the degree of consensus on a given topic (Morgan and Kreuger, 1993). In this qualitative approach culture was of importance and therefore focus group interviews contributed to examining this culture.

Focus group interviews complimented other methods and contributed to triangulation (Morgan, 1988). Kitzinger (1994; 1995) suggested that the interaction between the participants highlighted their view of the world, together with their values and beliefs about a situation. Focus groups benefited participants as they provided an opportunity to be involved in the decision making process (Race et al, 1994). Participants felt valued as experts, and were given the chance to work collaboratively with the researcher (Goss and Leinbach, 1996) as well as the focus groups being empowering for many participants. Additionally, they provided the opportunity for prominent issues to emerge together with their associated concerns.

There were limitations in terms of the ability to generalise findings to a whole population (Gibbs, 1997). Limitations are expressed when the group is not homogeneous (Morgan, 1988). However, all the participants in the focus group interviews were known to each other.

3.2.2 Semi-structured Interviews

Semi-structured interviews were conducted with patients, family members, GPs and the representative of the NCM. Semi-structured interviews were chosen as they had the advantage of providing enough structure to ensure that the interview produced rich and in-depth data relevant to the specific research question together with allowing topics to emerge that were not included in the interview schedule (Gibson and Brown, 2009). In addition, Gibson and Brown (2009) suggested that these types of interviews were based on the notion that the researcher tried to fit their pre-defined research interests into the unfolding topics that were discussed. This ensured that I collected similar types of data

from all the participants. I was able to word questions instinctively and this helped to develop a conversational style during the interview that focused on the topic (Patton, 2002) which would not be possible in focus group interviews. For the patients and family members this conversational style helped to relax the participants. Although the semi-structured interviews followed an interview schedule, they afforded me the latitude to vary the order of the questions according to the flow of the conversation.

3.2.3 Observation Methods

Observational methods tend to depend on waiting for things to happen in contrast to the researchers interview guide in a focus group (Gibbs, 1997). Participant observation provides a mechanism to learn the culture or subculture of the participants under study (Hammersley and Atkinson, 2007). Observational dimensions and their accompanying descriptions of significance were recognised by Spradley (1980). These included space, the participants involved, activities undertaken, the sequencing of events, goals to be accomplished and emotions experienced. Observational methods usually focus upon specific features that are of relevance and that occur within the research setting and were therefore deemed to be of relevance to this research study.

3.3 Sampling of Research Sites

In qualitative research the type of sampling employed is determined by the methodology selected and the topic under investigation (Higginbottom, 2004). As qualitative research cannot be critically appraised in the same way as quantitative research, the anti-realist approach is realised on the basis that existing principles and rules for sampling do not apply (Mays and Pope, 2000). Following exploration of the principles of sampling in qualitative research, and the systematic approaches to generation of study samples purposive sampling was deemed to be appropriate for this research. Purposive sampling is defined by Crookes and Davis (1998:81) as “judgemental sampling that involves the conscious selection by the researcher of certain subjects or elements to include in the study”. According to Patton (1990:169) “logic and power of purposeful sampling lies in selecting information-rich cases for study in depth. Information-rich cases are those from which one can learn a great deal about issues of central importance to the purpose of the research, thus the term purposeful sampling”.

In a qualitative approach, sampling is concerned with the selection of key participants to give insight into the phenomena under study, but also with sampling across time and

place (Mackenzie, 1994; Woodgate, 2000). When the aim is to achieve depth rather than breadth, as in this qualitative approach, participants were purposively selected based on their roles, knowledge, insights, and willingness and ability to discuss their experiences (Baillie, 1995; Roper and Shapira, 2000; Hammersley and Atkinson, 2007).

In this qualitative approach, selection was made in relation to the participant's membership of the community under investigation (Higginbottom, 2004). Sampling was determined by the number of participants in the community under investigation. The study sample size in this qualitative approach was therefore the total community under investigation. Key informants were significant in the generation of study samples. Roper and Shapira (2000) pointed out that key informants were individuals who may be gatekeepers but enabled the researcher greater access to the study population. Additionally, they are also able to reflect upon cultural practices and share this knowledge with the researcher.

Three major domains in qualitative research associated with sampling were focused upon people, time and context. The heterogeneous sample of participant's in this study were the CNSPC, patients, family members, GPs, PHNs and representative from the NCNM. A heterogeneous group membership supported qualitative research as well as aiming for a wide diversity of views (Kitzinger, 1994). The participants were selected according to the research aim and objectives (Ezzy, 2002; Reed et al, 1996). Kerlinger and Lee (2000) suggested purposive sampling relies heavily on the researcher's knowledge about the characteristics of the population that are relevant for the research. My background in palliative care nursing enhanced my knowledge of the population. Finally the sample decisions were guided by to the research interpretive framework (Miles and Huberman, 1994).

3.3.1 Settings

Higginbottom (2004) indicated that the goal for achieving heterogeneity in purposive sampling is to add rigor to possible empirical generalisation derived from the data and from the fullest range of participants and settings. The research took place in different geographical locations in a variety of settings. The geographical locations spanned both urban and rural covering a population of both greater than 500,000 and less than 500,000 in two health areas. Participants from both health areas partook in the study. The participants chose the most suitable interview setting and time for them. For the patients and family members all the interviews were held in the home. Two of the CNSPC focus

group interviews were held in the work setting and three were held off site. All the PHN focus group interviews were held in the work setting. One GP chose to be interviewed in the home and the other was a telephone interview. The representative of the NCNM was interviewed in the work setting. The non participant observation was conducted in the team meeting rooms. Data collection took place over a 6 month period which provided variation in time and resulted in different influences on participant's experiences.

3.4 Inclusion and Exclusion Criteria

The inclusion and exclusion criteria utilised for each of the participant groups in this study is presented in Table 1. The inclusion criteria referred to the characteristics of each of the participant groups who were part of the sample (Fawcett and Garity, 2009). Exclusion criteria referred to characteristics that excluded participants from being part of the sample (Fawcett and Garity, 2009).

Participant	Inclusion Criteria	Exclusion Criteria
Patient	The patient was under the care of the CNSPC for the previous four weeks.	The patients, condition deteriorated prior to interview
	The patient was both physically and psychologically able to participate in an interview lasting between forty five minutes and one hour.	The patient had impaired cognitive function
	Confirmation was received from both the patient's GP and the CNSPC that the patient's prognosis was of six months or less	The patient was unable to proceed with interview
	The patient provided informed consent to partake in the research study	
	The patient was not cognitively impaired	
Family Member	The family member was involved in caring for palliative care patient and under the care of the CNSPC in the previous four weeks.	The family were unable to proceed with interview
	The family member is in a position and psychologically able to participate in an interview lasting between forty five minutes and one hour.	
	The family member provided informed consent to partake in the research study	
Community CNS in Palliative Care	The CNSPC was a member of the Specialist Palliative Care team in the community in the South of Ireland	The CNSPC has been on career break, maternity leave or long term sick leave
	The CNSPC was in post for at least twenty four months	The CNSPC holds the position of community staff nurse in palliative care in the South of Ireland
	The CNSPC provided informed consent to partake in the research study	
Public Health Nurse	The PHN was a member of the PHN Service or Primary Care Team (PCT) for the previous twenty four months	The PHN has been on career break, maternity leave or long term sick leave

	The PHN was in post for at least twenty four months	The PHN holds a specialist PHN position
	The PHN had delivered care for a patient requiring palliative care approach to care in the previous twenty four months	
	The PHN provided informed consent to partake in the research study	
General Practitioner	The GP held a general medical card scheme list	The GP has been on career break, maternity leave or long term sick leave
	The GP was in post for at least twenty four months	The GP is on the GP training scheme
	The GP had delivered care to a specialist palliative care patient in the previous twenty four months	
	The GP provided informed consent to partake in the research study	
Representative of the NCNM	The representative of the NCNM was a RGN for previous two years	The representative of the NCNM has been on career break, maternity leave or long term sick leave
	The representative of the NCNM has responsibility for ratifying application for CNS.	
	The representative of the NCNM provided informed consent to partake in the research study	

Table 1: Inclusion Exclusion Criteria for Participants

3.5 Interview procedure

As I was conducting qualitative research, I was cognisant that I needed to take time to plan how to gain and maintain access to the research site (Gelling, 2014). I had to ensure that adequate time was spent in the research setting and consider how my participation in the research affected my data collection and analysis. The ethical considerations that guided this study are discussed later in this chapter in 3.8. The procedure involved in recruiting and interviewing each of the participant groups will now be described.

3.5.1 Phase 1 CNSPC Recruitment

All the Directors of Nursing (DoNs) /Nurse Managers of the CNSPC services in Health Area 1 and Health Area 11 were contacted. I made the initial contact by letter (Appendix 1). This was followed by a telephone call informing them of the study. Permission was sought from each Director of Nursing (DoN)/Nurse Manager to meet with the CNSPC teams to inform them of the nature and purpose of the study and invite their participation. Brief presentations were delivered to the CNSPC and written information offered to potential participants (Appendix 2). The topic of investigation was explained clearly before the participants agreed to participate in focus group interviews. In addition, at the presentations I requested the opportunity to undertake non participant observation in the MDT team office base setting.

3.5.2 Phase 2 Patient and Family Member Recruitment

At the meeting with the CNSPC details were highlighted on the benefits of the patient and families participation in this study. The CNSPC were invited to consider patients and family members who would be suitable and able to participate in the study. The inclusion/exclusion criteria were discussed. The CNSPC/Nurse Manager was invited to discuss participation in a potential interview with any patient and family member deemed suitable. Where a patient and family member agreed, a letter was forwarded to the CNSPC (Appendix 3) together with a patient and family information pack (Appendix 4, 5). The CNSPC was also requested and agreed to forward a letter (Appendix 6) to the patients GP informing him/her of the patient's decision to take part in the study.

3.5.3 Phase 3 PHN Recruitment

The Directors of Public Health Nursing (DPHN) in Health Area 1 and Health Area 11 were initially contacted by letter (Appendix 7). This was subsequently followed by telephone call informing them of the study. Permission was sought to meet the PHN teams and invite them to participate in the study being conducted. Three DPHN responded and agreed that they supported a focus group interview being held with PHN who were interested in participating. An Assistant Director of Public Health Nursing (ADPHN) subsequently contacted me. A suitable date, venue and time were agreed with the ADPHN and the letter of invite and PHN information leaflet (Appendix 8) was issued to the PHNs in each area.

3.5.4 Phase 4 GP and Representative of the NCMN Recruitment

The Irish College of General Practitioners, Dublin and Director of Nursing at the NCMN were contacted by letter (Appendix 9, 10). This was followed by a telephone call to invite GPs and a representative of the NCMN respectively, to participate in the study.

3.6 Data Collection

The theoretical framework guiding this research was role theory and this influenced my decisions when I considered data collection instruments. Goode (1960) purports that the total role system is unique and therefore, I had to consider the most appropriate instruments in which to capture the role of the CNSPC. Similarly, I had to be mindful of the role performances I required to represent role theory. Being cognisant that Brooks et al (2007) previously positioned role theory in exploring the perceptions of health care professionals through their interactions within organisations in the delivery of care to patients and families, I recognised that more than one data collection technique was required.

By being there in the field, I was the prime instrument of data collection. Multiple data collection techniques were used to gather the data. These included focus group interviews, semi-structured interviews, non participant observation and demographic data. There was an inherent value in generating a depth of data sources to give a richer and more comprehensive picture of the study. The interviews conducted will now be presented initially commencing with the pilot study.

3.6.1 Pilot Study

The focus group method was piloted with the first CNSPC interview. The pilot interview afforded me the opportunity to establish if the research technique was effective (van Teijlingen and Hundley, 2001). Frankland and Bloor (1999) recognised that piloting provided the qualitative researcher with a “clear definition of the focus of the study” which in turn assisted me in concentrating data collection on a narrow spectrum of projected analytical topics. The pilot study was conducted for a range of different reasons as identified by van Teijlingen & Hundley (2001). Initially, this included testing the adequacy of the research instruments. Then it established if the research technique was effective. Preliminary data was collected and the proposed data analysis techniques were assessed in order to uncover potential problems (van Teijlingen and Hundley, 2001).

This process was significant as it uncovered my need to engage more in the interview and questioning technique. Other problems such as poor recording were identified. A number of limitations of pilot studies have been identified by van Teijlingen and Hundley (2001). These included concerns about including participants from the pilot study in the main study (van Teijlingen and Hundley, 2001). However, I did not exclude these participants as this would result in a smaller sample in the main study. Instead, in subsequent focus group interviews I engaged more in the interview process and probed more in the questioning technique. In addition, I used two dictaphone recorders in case of malfunction.

Piloting of this focus group interview improved my confidence as a novice researcher (Holloway, 1997). Additionally, van Teijlingen and Hundley (2001) suggested that as researcher, I had an ethical obligation to report issues that arose from all parts of the study. This included the pilot phase and to report in detail the actual improvements made to the study design and the research process. The pilot study was beneficial in that it provided me with confidence that the recruitment approach was successful. I was offered the opportunity to recognise that spontaneity and probing of the questions was paramount. It highlighted that problems can occur with equipment. Most significantly, it provided preliminary data and offered the opportunity to assess the proposed data analysis techniques. As part of the pilot, I was able to scrutinise my role in the interview process. In addition, I was able to challenge my experience as a practitioner and whether my views and biases were interacting with the participants in my understanding and interpreting of the narratives (Darlaston-Jones, 2007).

3.6.2 Equipment.

Data management methods included recording, transcription, transcript checking, and the use of computer-assisted analysis software (Carter and Little, 2007). A dictaphone was used to record and NVivo 10 was the chosen computer assisted analysis software.

3.6.3 Interview Process

The process of the interview allowed for both the emergence of the individual experience and the creation of a combined understanding of the role of the CNSPC (Darlaston-Jones, 2007). Through interview techniques I explored the experiences of the participants in my study and uncovered the meaning the role of the CNSPC had for them (Darlaston-Jones, 2007). As researcher I was present with the participants through the interview and therefore the only person who experienced the entirety of the interview. This included the body language, intonation and hesitation that occurred through each interview which contributed to meaning and understanding of the whole experience (Darlaston-Jones, 2007). When patterns emerged in the process of the interview, I had the opportunity to obtain feedback from the participants (Aronson, 1992). The feedback then established the next question in the interview (Aronson, 1992). I had to be constantly receptive to the body language and tones of the participants' voices (Leggard et al, 2003). Therefore I had to anticipate the likelihood of emotional responses and be adequately prepared for them (Ashton, 2014). All the interviews conducted in both health areas and the number of participants in each focus group interview is presented in Table 2.

Participants	Health Area 1 (Population Greater than 500,000)	Health Area 2 (Population Less than 500,000)
CNSPC	2 Focus Group Interviews 4 – 6 participants in each interview Total 10 participants	3 Focus Group Interviews Including pilot interview. 4 participants in each interview Total 12 participants
Patient	2 Semi structured interview	2 Semi structured interview
Family member	2 Semi structured interview	1 Semi structured interview
PHN	2 Focus Group Interview 6 participants in each interview Total 12 participants	1 Focus Group interview 7 participants in interview Total 7 participants
GP	1 Semi structured interview	1 Semi structured interview
Representative of the NCNM	1 Semi structured interview	

Table 2: Focus Group and Semi structured interviews conducted

3.6.4 Phase 1 CNSPC Focus Group Interview

The interview schedule (Appendix 11) details the line of questions. Prior to each focus group interview the CNSPC was invited to complete a Demographic Data Questionnaire (Appendix 12).

3.6.5 Phase 2 Patients and Family Semi-structured Interviews

The interview schedule (Appendix 13, 14) details the line of questions. One patient had requested that a family member would not be interviewed. Similar to Hudson et al (2005) who attributed gate-keeping as a desire to protect persons from distress or being overburdened this patient did not want to put the family member under undue pressure and wanted to protect them. In this instance the patient made the decision on the family members behalf that it would be in their best interest not to participate (Seymour et al, 2005; Ewing et al, 2004). This resulted in three family members participating in the semi structured interviews. The CNSPC accompanied me to the home of P1 and F5 and made

the necessary introductions. I contacted P2 and P4 prior to the interview to receive directions. The CNSPC arranged the most suitable time for P3 and provided directions to the home.

During the pre-interview phase, there was much small talk (Corbin and Morse, 2003). For three of the four patients, the family member remained present from the pre-interview phase to completion of the interview. Patients had requested the family members to remain present. Though the study concerned the role of the CNSPC, patients spoke openly about their condition and feelings in the presence of the family. On occasion the family members also joined the conversation. Following the patient interviews, two of the patients left their respective rooms and allowed their family members to be interviewed alone. At this time, family members were very forthcoming on the impact the illness had on them.

The time in the pre-interview phase allowed the participants and me to assess each other and begin to establish a degree of trust (Corbin and Morse, 2003). This initial period was most important as it set the tone for the subsequent interview (Corbin and Morse, 2003). It was important not to hurry as this was the beginning of a temporary but important connection that grew and intensified over the course of the interview (Corbin and Morse, 2003). This was also the period in which the groundwork for reciprocity (Schoenberg, 2002) was established. As researcher, I chose to share information about my own life and particularly why I had an interest in the research topic (Thompson, 1995).

3.6.6 Phase 3 PHN Focus Group Interview

The interview schedule (Appendix 15) details the line of questions.

3.6.7 Phase 4 GP and Representative of the NCNM Semi Structured Interviews

The interview schedules (Appendix 16, 17) details the line of questions.

One GP interview was conducted over the telephone in the evening at the request of the GP. Both the time and the setting were deemed most suitable by the GP. Telephone interviewing can be more popular for geographically scattered participants. This GP was located in a rural and distant geographical location. Telephone interviews can raise doubts about the quality of the data, compared with face-to-face interviewing (Thomas and Purdon, 1994). However, the interview was recorded on a dictaphone and no

difficulties were encountered concerning the quality of the data. Thomas and Purdon (1994) also suggested that as in the case of face-to-face interviewing, a great deal depends upon the level of interest and involvement aroused by the subject matter. The telephone interview was conducted outside of the working day when the GP was able to partake and be fully involved, interested and concentrate on the subject under discussion.

The second GP interview was conducted as a face to face interview. This was conducted in the GPs home, as requested. Again this interview was conducted outside of the working day at a time most suitable for the GP.

The interview conducted with the representative of the NCNM was held in a meeting room deemed most suitable for the participant.

3.6.8 Non Participant Observation

I sat in on two CNSPC team meetings one in each Health Area. This provided me with the opportunity to get a sense of the interaction and dynamics between the different members of the team. These meetings were held in each team base and so I was in the space to observe the surrounding, and activities that the CNSPC was involved in. In addition to the team meeting, telephone calls were received and made and again I was afforded the opportunity to observe the skills required in dealing with patients and families and healthcare professionals. The team meeting set the tone for the working day. Non participation observation provided me with a mechanism to use these observations informally to reflect on what was happening at these team meetings. Within my reflective diary I recorded my observations, the surroundings, the interactions and activities. Later when I was analysing my data, the observations helped me to develop my themes by providing insight into work patterns. A combination of qualitative methods in both the gathering through visual and verbal and then the analysis of the data through thematic analysis (Long and Godfrey, 2004) allowed me to understand the role of the CNSPC.

In addition non participant observation was of particular benefit to me within the focus group interviews when the CNSPC' were talking about their roles and I could now understand the remit and extent of the role. I had now been afforded the opportunity to touch the core of what was going on (Greenhalgh and Taylor, 1987) and to grasp an element of what the CNSPC' were alluding to in these interviews. As a result of the observations I was able to understand the unspoken cultural expressions and had a more explicit understanding of the role.

3.6.9 Reflective Diary

I began to record a reflective diary from the first presentation to the CNSPC team through to the data collection, thematic analysis process and reporting. The reflective diary allowed me time away from my fieldwork for recording my reflections, the subsequent interpretation of the reflections and what this meant for my thematic analysis and findings. My reflective diary was very beneficial in evaluating my performance at my first interview as suggested by Darawsheh (2014). This resulted in a need for me to make changes to my performance thus enhancing the process and providing value for the participants and the resulting interpretation of the findings.

Through reflexivity, I had continuously to reflect on my values, preconceptions, behaviour and those of the participants which could have affected the interpretation of the responses. I found my research diary of particular importance in raising my awareness to particular influences on my relationship with the research topic, the participants and then interpreting the data. As all the patient participants lived in houses I had a preconception of each of their backgrounds. However, my assumption was incorrect and as I learned when I met one of the participants who came from a minority ethnic background. I had to examine my values and taken for granted assumptions to ensure that these did not affect the interpretation of the data. Through reflexivity, my reflective diary went from an audit trail for analysis to a reflection on the political and social constructions that influenced both the research topic and me as researcher (Koch and Harrington, 1998).

3.6.10 Reflection on Focus Group Interviewing

Organising focus group meetings required planning in order to arrange the participants to the group interviews. Setting up appropriate venues that suited the group was time consuming. Powell et al (1996) suggested that neutral locations can be helpful in avoiding either negative or positive associations with a particular site. However, locations were chosen that were most suitable to the particular focus group. The focus group interviews were held in the work setting or off site in a rented facility. The venues for the focus group interviews were agreed by the participants. Times were agreed with each focus group prior to the meeting. Both refreshments and sitting round in a circle helped to establish the right atmosphere. The participants were informed from the outset that I would be taking notes and checking the recording equipment during the meeting (Gibbs, 1997). Full information about the purpose and uses of participants' contributions were given

before the interviews commenced. Participants were reminded of the confidential nature of what they heard during the meeting and as researcher; my responsibility was to anonymise data from the group. I conducted the focus group interviews alone and discussed this further in the reflexivity section. As each meeting was pre-planned, I had organised my equipment prior to each meeting.

My role was critical, particularly in terms of providing clear explanations of the purpose of the group, as well as assisting participants feel at ease, and facilitating interaction between group members. Through the meeting I needed to promote debate and achieved this by asking open questions. On occasions I needed to draw out participants differences, and tease out a diverse range of meanings on the role of the CNSPC. Alternatively, I needed to probe for details, or move things forward when the conversation was drifting or had reached a minor conclusion (Gibbs, 1997). I also, on occasions, needed to keep the sessions focused and so sometimes had to steer the conversation back on course. It was not necessary to encourage any of the participants to speak, as all participants contributed at each meeting. I had to be cognisant to avoid giving personal opinions so as not to influence participants towards a particular position or opinion. I found my role as interviewer demanding and challenging. I had to be mindful of my interpersonal skills. These included being a good listener, non-judgmental and adaptable, as identified by Gibbs (1997). It was important that the participants' had trust in me.

I found the interviews an exciting challenge, as I tried to gain different perspectives on my area of interest. This interpersonal communication was important as it highlighted cultural values and group norms. The focus groups were particularly useful in examining work place cultures, for example how the CNSPC and PHN copes working with palliative care patients. The focus group was a mechanism for the participants to provide mutual support in expressing feelings that were common to the group but which they considered deviated from mainstream culture (Kitzinger, 1995). This was a method that facilitated the expression of criticism for some focus groups and facilitated the exploration of different types of solutions and invaluable in improving services. These focus groups were particularly suitable as they reflected the attitudes and experiences of the participants. This provided the opportunity and mechanism to examine how ideas developed and operated within the given cultural context of caring for the palliative care patient in the community.

3.7 Transcription

Transcription is an integral process in the qualitative analysis of language data (Lapadat and Lindsay, 1999). As researcher I made the choice to transcribe the data recorded where the process of transcription is both interpretive and constructive (Lapadat and Lindsay, 1999). My decision to transcribe the tapes enhanced the trustworthiness of the data. Transcription is an essential step for research to achieve thoroughness, accuracy, and retrievability (Lapadat and Lindsay, 1999)

In addition, I was able to immerse myself in each interview and setting as I transcribed. I included um's, ah's, pauses and gestures in the transcriptions. Mishler (1991) extended the argument that transcription is fundamentally interpretive but agrees that processes of transcription form an important contribution in the production of scientific knowledge. When transcribing, Lapadat and Lindsay (1999) recognised that the researcher makes many procedural and methodological decisions which reflect their theoretical assumptions and rhetorical purposes. Time was one of the disadvantages of transcription in practice settings identified by Bertrand et al (1992) and Gravois et al (1992), which subsequently prolonged the time to the analysis stage (Gravois et al, 1992).

3.8 Ethical Considerations.

When research is conducted with sensitivity and guided by ethics, it becomes a process that benefits participants and the researcher (Corbin and Morse, 2003). To address the moral complexities of the research relationships, I had to be sensitive to the needs of all participants but particularly the patients and family members from conception of the research to the reporting of findings (Hewitt, 2007). Patton (1990; 2002) recognised that empathy communicates interest and concern for participants, and for the findings to be credible that there needed to be a balance between empathy and neutrality. Empathy developed from personal contact with the participants being interviewed and involved being able to take and understand the positions, feelings, experiences and world views of others (Patton, 1990). In contrast, neutrality is a non-judgemental approach that encourages empathy but also allows the researcher to develop a rapport with the participants (Patton, 1990).

This section will now provide details of the ethical approval process, ethical principles applied to the study, power relationships, informed consent, vulnerability and research and data protection.

3.8.1 Ethical Approval

Ethical approval was sought from the School for Health, School Research Ethics Approval Panel, University of Bath, UK, ethical committees in Health Area 1 and Health Area 11 in the south of Ireland to conduct this study. Formal ethical approval was granted from the University of Bath (Appendix 18) and ethical committee in Health Area 1 (Appendix 19) to proceed with the research. At ethics committee interview in Health Area 11, concerns were expressed that palliative care patients were to be included as participants and that these patients would be cognitively impaired as a result of opioid medications. This was addressed by confirming that interviews are more beneficial than harmful as indicated by Corbin and Morse (2003). The procedure to access patients was identified. Though Corbin and Morse (2003) contend that there is evidence that qualitative interviews may cause some emotional distress, there was no indication that this distress was any greater than in everyday life or that it required follow-up counselling.

Additionally, the committee were reassured that though cognitive function is a recognised complication of opioids that misconceptions surround the nature and prevalence of its occurrence (Lawlor et al, 2000). Inclusion and exclusion criteria were discussed and an additional inclusion criterion was added that “the patient was not cognitively impaired” and ethical approval was granted (Appendix 20).

3.8.2 Ethical Principles Applied to this Study

Ethics provides the basis for conduct in research (Davis, 1990; Munhall, 1988; Punch, 1986) and is acquired through discourse and reflection on one’s own and others’ experiences. Reeves et al (2008) suggested that the direct interaction that occurred between researchers and health care professionals during fieldwork can be regarded with suspicion, as traditionally health services research viewed researchers’ as detached rather than involved. As researcher, it was necessary for me to examine my motives and scrutinise my actions and the research processes for both foreseeable and unforeseeable consequences that could affect the participants (O’Neill, 1989; O’Neill and Trickett, 1982; Robson, 2002). It has to be acknowledged that no one can predict what will be said in the course of an interview, the feelings it will provoke, or indeed any long-lasting effects (Corbin and Morse, 2003). An issue of significance for me as researcher was the need to judge and respond to the emotional state of the participants (Kavanaugh and Ayres, 1998), where necessary.

Davies and Dodd (2002) suggested that ethics form an essential part of rigorous research. Ethics are an integral part of rigor and are intertwined in the approach to research, through the way questions are asked, how answers are responded to and then the way researchers reflect on the material. An implicit part of ethical practice for me involved acknowledging where I was situated in the research process. This accountability began by making visible, the research process as recommended by Davies and Dodd (2002). My interest concerned understanding the social concerns around the role of the CNSPC from the perspective of health care professionals, patients and family members.

I also needed to be mindful that collecting data in a natural environment raised important ethical issues, identified by Oliver (2010). Firstly, this involved the cementing of relationships and building of trust. The second was the establishment of firm boundaries around the research field, as it was impossible to control who entered the observation zone (Murphy and Dingwall, 2001; Moore and Savage, 2002). Fetterman (1998) suggested that directly linked to this was honesty and trust which are predominantly communicated through self-presentation and general demeanour, and are critical qualities to consider for every qualitative effort. My role as an “insider” and the ethical implications of this are discussed in 3.12 Reflexivity.

3.8.3 Power Relationships

All participants were aware of the fact that I had held a nursing position in the past. Indeed, I was known to some of the participants, where I had held a managerial position in a previous role. However, at the time of data collection I did not have a clinical or managerial relationship with any of the research participants. I have to acknowledge that I initiated the study, decided on the questions and invariably I held and interpreted the participants’ data (Brinkmann and Kvale, 2005) and created the final analysis. Trowler (2011) recognised that researching colleagues can raise ethical issues concerning disparities in power. As researcher, I had to be mindful of the power relationship with the participants where I had the power as the seeker of knowledge and the participants have the power as the holders of knowledge (McDermid et al 2014). This invariably had the potential to change my relationship with the participants who held the knowledge that I sought. Careful negotiation and understanding of the ethical implications of beneficence on my part was important to obtain that information (Karnieli-Miller et al, 2009). Obtaining informed consent was an ongoing process of renegotiation throughout research, as risks can never be predicted fully and unforeseen issues can arise (Munhall,

1990; Usher et al, 1998; McIlfatrick et al, 2006; Josselson, 2007). In addition according to Parahoo (1997), by adhering to the ethical principle of justice this ensured fair and equitable treatment of all the participants.

I had to be cognisant that in my role as interviewer there was the potential for this to have positive or negative results. Tunnah et al (2012) describes how being interviewed by a familiar person may be less threatening, and therefore lead to a more relaxed discussion. This more relaxed discussion did allow participants to voice issues of concern. Being mindful of the conflict that may occur for participants where they unintentionally provide information because of a trusting relationship I had to be very cognisant of the need to consider the confidentiality (Mercer, 2007) of the participants with any of the reported findings. At all times I aimed to maintain professionalism with strict boundaries that protected the rights of the research participants.

In contrast the nurses may have felt inhibited because I was known to them. This may be particularly pertinent during recruitment where participants may feel pressured and believe they have no choice but to take part in the study due to the pre-existing relationship (McConnell-Henry et al, 2009/10). Similarly, the patient and family members may have wanted to portray a positive picture for fear that a more negative scenario would impact on their future care and treatment. To address the voluntary nature of participation in the study was important so that patients and family members would not fear any adverse consequences if they did not participate (McDermid et al, 2014). Furthermore, information packs outlining the risks and benefits of taking part in the study were offered to all potential participants. This identified the right to withdraw as a participant at any stage of the process without explanation, consequence or repercussions (McIlfatrick et al, 2006). Nonetheless, during data collection I did not sense that any of the participants felt awkward at any time.

3.8.4 Informed Consent

It was necessary that participants fully understood what it meant to participate in terms of risks and benefits (Corbin and Morse, 2003). Where cultural differences and language barriers existed it was important that I ensured the participants fully understood. It was my responsibility to make certain that participants understood their rights, especially the right not to participate or to withdraw from the research at any time (Corbin and Morse, 2003), without giving a reason and that this would not affect the standard of care they received. This was designed to ensure that consent was freely given and to acknowledge the

potential vulnerable position the patient may feel with their treating team (Data Protection Commissioner, 2007). Accordingly, this safeguarded the context for seeking consent of the patient and separated any direct linkage with the patient's treatment. The benefits of research to participants should outweigh the risks. Beyond emotional risks, I was not aware of any social, political, legal, and economic complications that might result for the participant in the research (Corbin and Morse, 2003).

This process ensured that the informed consent of the patient and other participants was obtained before the research was conducted. The contents of the consent form were read prior to each interview (Appendix 21, 22, 23, 24, 25, 26). Each participant received a signed copy of the consent form and I kept a copy. This complied fully with the Data Protection Act in Ireland (2007) obligations. In addition through this procedure all participants were informed of their right to revoke their consent at a later date if so desired. The advantage of this approach was that all participants were informed of the use of their data and were able to decide based on the information provided in the information leaflets, as to whether they would be agreeable to their data being used in such a manner (Data Protection Commissioner, 2007).

3.8.5 Vulnerability and Research

Lee and Renzetti (1990) suggested that there is always a risk that interviews on certain topics can be sensitive and arouse powerful emotions. These topics delve deeply into the personal life or experiences of the participants, which was not the aim of this study (Corbin and Morse, 2003). Additionally, I was interested in hearing the patient and family members' stories and showed empathy where necessary. Jarrett et al (1999) highlighted the particular vulnerability of terminally ill patients, especially within an interview situation where the patient or family member talks about aspects of their life, care and illness which are new or threatening to them.

Parkes (1995), Addington-Hall (2002), Sque (2000), Dyregrov (2004), and McPherson and Addington-Hall (2004) recognised that recruiting participants to be interviewed about sensitive life events can be challenging. This was attributed to potential distress of the interview and the vulnerability of the participants (Addington-Hall, 2002). Addington-Hall (2002:223) stated that "the frailty of palliative care patients presents challenges in deciding on appropriate data collection methods and tools".

As researcher, it was incumbent on me to recognise and be sensitive to the moral issues related to vulnerability of the patients and family members and to the potential impact of the research on the participants (Benzies and Allen, 2001). Of importance was my recognition and sensitivity to my role in the construction of participants meaning when I posed questions during the interview.

3.8.6 Data Protection, Confidentiality, and Anonymity.

This research study was carried out in a manner consistent with the framework of the data protection legislation as detailed in the data protection guidelines on research in the health sector (Data Protection Commissioner, 2007) and as per Data Protection Act in Ireland (2007). The guidelines set out the legislative position as contained in the Data Protection Act (2007) of what is expected of a health professional, seeking to access patient identifiable data for research purposes in terms of ensuring the fundamental rights and freedom of the patient (Data Protection Commissioner, 2007).

As the data was being collected as part of a doctorate programme, information was included to confirm that university staff may view the data. I was also mindful of my professional obligation and potential situations where confidentiality would have to be over-ridden (Mather's et al, 2002). My professional obligation negating such reporting concerned the disclosure of patient distress or issues relating to the delivery of sub-optimal practice. The obligation to report such concerns was included in the explanation of confidentiality in the information leaflets for potential participants (Dean and McClement, 2002).

The information leaflets (Appendix 2, 4, 5, 8, 9, 10) did provide assurances and details concerning the safeguards in place designed to protect the potential participant's confidentiality. An outline was provided of the research to be conducted. In addition, assurances were given that all data would be anonymised. Data was anonymised to protect participant's identify. Anonymisation of the data was an automatic process performed as the participant's interviews were being transcribed where code numbers and letters were allocated to all of the participants. Table 3 lists the coding and the details are explained in the text underneath the table. The list of names and corresponding identifiers were stored separately and securely. Appropriate safeguards were put in place to ensure that participants personal data and interview transcripts were only used for this study, and could only be accessed or further disclosed to the persons intended. Data collection was undertaken according to the regulation set out in the 1998

and 2003 Data Protection Acts in Ireland (2007). Comprehensive security and access controls in relation to the storage of manual and electronic data were key requirements. All audio-tapes and demographic data of all participants were stored in a locked cabinet in a locked room. The computer storing research equipment containing all the study details and information was encrypted. As part of the university requirements, all the data will be stored for at least 5 years in a locked cabinet under the supervision of the researcher.

Participants and institutions	Abbreviations
Community CNS in Palliative Care or Home Care Nurse	Alphabetical Letter and Number CNS A1 – CNS V4
Public Health Nurse	Alphabetical Letter and Number PHN A1 – S1
General Practitioners	Alphabetical Letter and Number GP A1, B2
Nurse Representative for the National Council for the Professional Development of Nursing and Midwifery	Alphabetical Letter N
Patient	Alphabetical Letter and Number P1 – P4
Family Member	Alphabetical Letter and Number F5 – F7
Town	Alphabetical letter Q – Z
Acute General Hospital	Alphabetical letter A – G
Older persons Hospital	Alphabetical letter H
Specialist Palliative Care Inpatient Unit	Alphabetical letter K
Consultant in Palliative Medicine	Alphabetical letter L, M

Table 3: Coding for Participants, Locations and Institutions.

The need to ensure confidentiality led to the need to refer to all participants in letters and numbers. Each CNSPC focus group was assigned the letters CNS and each CNSPC assigned a letter and number. The PHN focus groups were assigned the letters PHN and a letter and number. The GPs were assigned the letters GP together with a letter and number. The representative from the NCNM was assigned the letter N. Patients were assigned the letter P and a number from 1 to 4. Finally family members were assigned the letter F and the number 5 to 7. A town was identified by an alphabetical letter ranging

from Q to Z. Each hospital was assigned an alphabetical letter such as A to G. In conclusion the specialist palliative care inpatient unit was identified by the alphabetical letter P and older person's hospital by the letter H. The Consultants in Palliative Medicine are referred to by a letter.

3.9 Data Analysis.

The researcher, as identified by Boyle (1994) and Hume and Mulcock (2004), tries to make sense of the data in terms of the emic, etic and scientific analytic perspectives. Graneheim and Lundman (2004) recognised the dichotomy of trying to remain faithful to the raw data and simultaneously recreating it to view the phenomenon under investigation in a new way.

On completion of each interview data was transcribed and transferred to the software package NVivo 10. Data analysis began when I started to notice and see patterns of meaning and issues of potential interest in the data (Braun and Clarke, 2006). NVivo 10 the computer assisted qualitative data analysis package aided with the thematic coding of the collected data. Data obtained from all the interviews was analysed using thematic analysis, a method described by Braun and Clarke (2006) for identifying, analysing and reporting themes within data.

Data analysis was undertaken in an inductive thematic manner which will be discussed in the following section. The procedure involved in the thematic analysis within each group and across the six groups to enable exploration of similarities and differences will be described (Charmaz, 2010). When interpreting the data, I had to be mindful of my position as an 'insider'. This is discussed in 3.12 Reflexivity.

3.9.1 Description of the Approach to Data Analysis.

Different qualitative analytic methods were considered. Those such as conversation analysis, (Hutchby and Wooffitt, 1998) and interpretative phenomenological analysis (Smith and Osborn, 2003) stem from particular theoretical or epistemological positions. Braun and Clarke (2006) suggested there is limited variability in how these methods are applied within pre-existing particular frameworks. Similarly, others such as grounded theory (e.g., Glaser, 1992; Strauss and Corbin, 1998), discourse analysis (Burman and Parker, 1993; Potter and Wetherell, 1987; Willig, 2003) or narrative analysis (e.g., Murray,

2003; Riessman, 1993) have different manifestations of the method, from within pre-existing broad theoretical frameworks.

Braun and Clarke (2006) also refer to methods that are independent of theory and epistemology, and can be applied across a range of theoretical and epistemological approaches. Thematic analysis was identified as such a method as it is not linked to a pre-existing framework and is compatible with both essentialist and interpretivist paradigms. Because of its theoretical freedom, Braun and Clarke (2006) contend that it provided a flexible and useful research tool that provided a rich and detailed, yet complex account of data. Thematic analysis was deemed as the most appropriate method of analysis for this study as it provided a way of seeing for the researcher, a way of making sense out of seemingly unrelated material and a way of analysing qualitative information.

3.9.2 Framework for Analysis

The six phases of framework analysis identified by Braun and Clarke (2006) were used to analyse the data. These included familiarising the data, generating initial codes, searching for themes, constructing the network, describing and exploring the thematic networks and summarising the thematic network and will these be presented now.

3.9.3 Familiarising the Data

The process of transcription provided an excellent format to begin familiarising myself with the data (Riessman, 1993). This resulted in a far more thorough understanding of the data. Bird (2005) argued that transcription should be a key phase of data analysis within interpretative qualitative methodology and Lapadat and Lindsay (1999) recognised this interpretative act as the initial stage, where meanings were created. It was vital that I immersed myself in the data where I became familiar with the depth and breadth of the content. This involved repeated reading of the data, and searching for meanings and patterns. I found it helpful to read through each data set at least once before I began coding, as my ideas and identification of possible patterns were being shaped as I read through the data (Braun and Clarke, 2006). I began to take notes and marked ideas for coding which I later returned to in subsequent phases. At this stage I felt I was ready to begin the more formal coding process.

3.9.4 Generating Initial Codes

The initial step in a thematic analysis is to reduce the data by dissecting the text into manageable and meaningful segments. This required a coding framework (Attride-Stirling, 2001). The coding framework was devised on the basis of the important issues that arose in the text together with the theoretical interests of symbolic interactionism. The codes were then applied to the data to dissect it into segments. These were meaningful sections of text such as passages and quotations which were necessary for a particular analysis (Attride-Stirling, 2001; Ritchie and Spencer, 1994). The codes in the coding framework had explicit definitions. This ensured they were not interchangeable and were limited in scope and focus explicitly on the analysis (Attride-Stirling, 2001). Coding was conducted manually. The data was coded by writing notes on the texts that were being analysed, to indicate potential patterns (Appendix 27).

3.9.5 Searching for Themes

The text segment in each code was reviewed and the important and significant themes were extracted. At this stage it was helpful to use visual representations. These helped to sort the different codes into themes. Both mind-maps and writing the name of each code on a separate piece of paper and subsequently organising them into theme-piles were helpful (Braun and Clarke, 2006). This allowed the researcher to reframe the reading of the text and subsequently enabled the identification of underlying patterns and structures. The data was then refined into a more manageable set of significant themes that summarised the text. As Attride-Stirling (2001) suggested these themes were specific enough to be discrete and broad enough to capture a set of ideas contained in numerous text. Identification of the themes required much interpretative work (Attride-Stirling, 2001). Each theme had to be specific enough to pertain to one idea, but broad enough to find incarnations in various different text segments (Attride-Stirling, 2001). It was at this time that I had to start thinking about the relationship between codes, between themes, and between different levels of themes. At this point, I began to have a sense of the significance of individual themes (Braun and Clarke, 2006). This process was undertaken for each data script separately.

3.9.6 Constructing the Network

The themes derived from the text were assembled into similar coherent groupings. These groupings were to become the thematic networks (Attride-Stirling, 2001). Decisions on

how to group themes were made on the basis of content and as appropriate on theoretical grounds. Each grouping eventually resulted in a distinct Global Theme, supported by its own discrete Organising and Basic Themes (Attride-Stirling, 2001). Each global theme produces a thematic network (Attride-Stirling, 2001) and these were illustrated in web like representation. The networks were refined by working from the basic themes, inwards to the global theme (Figure 1). The objective was to summarise particular themes in order to create larger, unifying themes. These then condense the concepts and ideas mentioned at a lower level (Attride-Stirling, 2001).

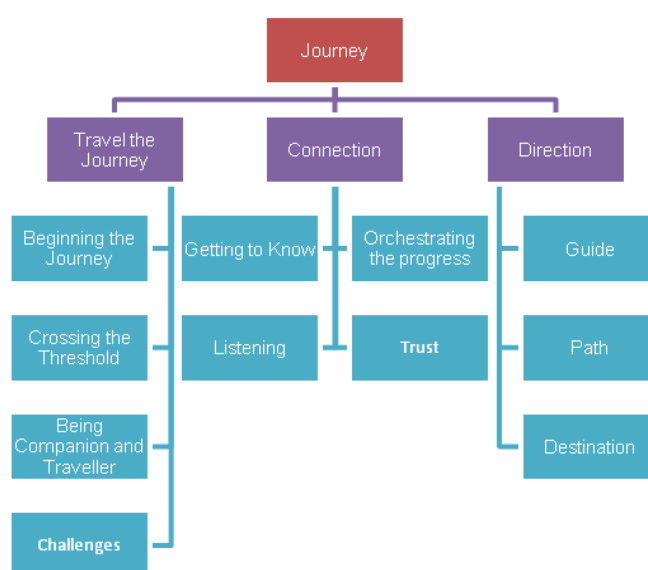


Figure 2: Thematic Network - Journey

3.9.7 Describing and exploring the thematic networks

As thematic networks are a tool in analysis, it was necessary to go deeper into the meaning of the texts. The themes that emerged had to be explored, identifying the patterns within them (Attride-Stirling, 2001). Once the networks had been constructed, it was necessary to return to the original text and interpret it with the aid of the networks (Attride-Stirling, 2001). Each network was taken in turn and its contents described by supporting the description with text segments (Attride-Stirling, 2001). As the description was being woven and as I began to explore, the underlying patterns began to appear (Attride-Stirling, 2001). As researcher, I returned to the original text and read it through the global themes, organising themes and basic themes (Attride-Stirling, 2001). At this stage I was immersed into a deeper level of analysis.

3.9.8 Summarising the Thematic Network

A summary of the main themes and patterns of each network were described and explored in full and presented in each thematic network.

3.9.9 Interpret Patterns

At this point it was important to return to the original research questions and the theoretical interests underpinning them, and address these with arguments grounded on the patterns that emerged in the exploration of the texts (Attride-Stirling, 2001). The key conceptual findings in the summaries of each thematic network were brought together into a cohesive story and related back to the original questions and the theoretical grounding of the research. In addition, it was necessary to propose some explication of the original questions grounded on the content and exploration of the texts, and on the theoretical constructs guiding the research (Attride-Stirling, 2001).

3.10 Use of Metaphor

At this time a metaphor “journey” used in conversation interviews was recognised to describe the role of the CNSPC. Aristotle’s *Poetics* defined metaphor as “the application of an alien name by transference” (Aristotle, 1457b). More recently, Lakoff and Johnson (1980) suggested that far from metaphors being devices of “poetic imagination”, they are “pervasive in everyday life, not just in language but in thought and action”, providing a source of coherence in our understanding of the world and helping us to understand something abstract in terms of something concrete or physical. Susan Sontag’s work ‘Illness as Metaphor’ takes an opposing view to that of Lakoff and Johnson (1980) (Sontag, 1978) and asserts that metaphors are not to be welcomed. However, Sontag (1978) agrees with Lakoff and Johnson (1980) that metaphors are a pervasive and everyday way of thinking and speaking about the world.

Blumer (1969) works with the concept of symbolic interactionism in which meaning itself is one of the interpretative processes used by the person. This study was guided by the theoretical perspective of symbolic interactionism (Blumer, 1969), where meaning was central to human behaviour, in that humans act toward people and things according to the meaning they have given to them (Griffin, 1997).

Lakoff and Johnson (1980) contended that metaphors of journeying were commonly called upon to facilitate the expression of patients' and professionals situations and therefore may give opportunities for personal growth, exploration and hope. There was another element to metaphors which allowed for verbalising sensitive issues, and a way that metaphors could bring distance to the patient's situation (Southall, 2012). Southall (2012) suggested that by avoiding the stark language of death and dying, metaphors allowed people to speak about their illness and the future in a new way. Indeed, as a rhetorical tool, metaphors can help depict experiences with language that goes beyond straightforward information oriented paraphrasing (Carpenter, 2008). In addition, Carpenter (2008) suggested that metaphors can be used to provide structure to the data, to understand a familiar process in a new light, to identify situation-specific interventions, and to evoke emotion. Similarly, metaphors can serve as a powerful strategy to portray complex realities (Miles and Huberman, 1994), and add depth of meaning to understanding (Kangas et al, 1998).

3.11 Rigor

Reliability in the qualitative sense is based on consistency and care in the application of research practices. This was reflected in the visibility of research practices, and reliability in the analysis and conclusions, and at the same time being mindful of the partiality and limits of the research findings (Davies and Dodd, 2002). My study involved the sharing of identities and a common social positioning with the participants, on the topic I was researching. In carrying out interviews, this encouraged a rapport based on a sense of shared understanding and empathy. I hoped to gain the trust of the patients, family members and the health care professionals to enable them to feel comfortable about articulating their opinions, feelings, thoughts, and experiences on the issues that were raised within the interview. In adopting these methods, my aim was as referred to by Davies and Dodd (2002) to ensure that my research was true to the material, meaningful, and alive with richly textured details and information.

Rigor was enhanced in this study through the triangulation of data collected from a number of samples and by continually searching for exceptions and negative evidence (Hammersley and Atkinson, 1995). Three processes were presented by Allen (2004) that augment the rigor of a study and contributed to assessing the validity of the study findings. The first includes relating with how I sorted the field of study by my interpretive lens. The second was my acknowledgment as researcher that I had an effect on the phenomena

being studied. The final was recognition, as researcher, that I was also affected by being in the field.

The research was carried out in ways that were sensitive to the nature of the setting and that of the phenomena being investigated (Hammersley and Atkinson, 2007).

Transparency was essential to develop the qualitative methodologies and to ensure that methodological rigour was maintained (Higginbottom, 2004). The credibility of qualitative studies can be enhanced by clear explication of the processes undertaken together with the steps used in sampling and establishing and by the empirical generalisability of findings (Higginbottom, 2004).

Rigor was maximised for my study through data collection and the analysis procedures I engaged in together with adherence to a number of processes recommended by and for qualitative researchers (Breen, 2007). For qualitative research terms such as credibility, dependability, confirmability, and transferability (Lincoln and Guba, 1985) are used to enhance rigor. I utilised a number of procedures to maximise the research rigor. As demonstrated in this chapter, I employed multiple sources of data and methods of data collection through semi-structured and focus group interviews, reflective diary, non-participant observation and demographic data (Morse, 1994; Patton, 2002; Strauss, 1987). As an audit trail, I kept a journal where I documented the tasks undertaken (Etherington, 2004; Lincoln and Guba, 1985; Morse, 1994; Strauss, 1987; Strauss and Corbin, 1990; 1998). I checked and discussed my interpretations with my supervisor to ensure accuracy (Maykut and Morehouse, 1994). Finally, I have provided a detailed description of the settings and the participants involved in the study so the credibility and transferability of findings could be applied to different contexts where there was similarity between the research setting and other settings (Burgess-Limerick and Burgess-Limerick, 1998). Finally, my role as an “insider” and the resulting impact of this on the methods of data collection together with my relationship with some of the research participants are discussed in the forthcoming section 3.12 Reflexivity.

In an effort to enhance the rigor of my study, I took the time to reflect on both my personal and the epistemological reflexivity and described what I considered my own beliefs on the phenomena being studied. I had to be aware of how my own experiences and knowledge would impact on various aspects of the research. This included the construction of meaning from the data collected. I commenced this from the start of the study but I remained aware of how reflexivity developed as more data was collected and as the analysis of the data progressed.

3.12 Reflexivity

As my study utilised a qualitative methodology reflexivity was necessary so that I could clarify my personal motivation for undertaking this research (Crotty, 1998; Etherington, 2004; Patton, 2002). In an effort to clarify my role in the research process, I had to consider my position as either an ‘insider’ or ‘outsider’ (Bonner and Tolhurst, 2002). Breen (2007) described ‘insiders’ as those who chose to study a group to which they belonged, and where ‘outsider’ researchers did not belong to the group under study. From this perspective, I believe I am an insider in this study. Advantages to being an insider to the research domain included an understanding of the group’s culture, the ability to interact with the group and have established relational intimacy with the group (Breen, 2007). As an ‘insider’ I had to be open, honest, and insightful about my role as researcher while being mindful of my background and how this shaped my interpretations through the analysis and findings of the research. As suggested by Corbin Dwyer and Buckle (2009), I was committed to accurately and adequately representing the research participants’ experiences in the data collection phase of the study. With my role as an ‘insider’ in data collection, I understood the professional language being used. Therefore, as discussed by Jootun et al (2009) following the interpretive process and data analysis, I understood the perceived true meaning within group conversations at that time, of the data that was later presented in the findings.

Understandably, there were disadvantages to being an ‘insider’. These included loss of objectivity in terms of making assumptions based on prior knowledge (DeLyser, 2001; Gerrish, 1997; Hewitt-Taylor, 2002). Breen (2007) suggested that ‘insiders’ can be confronted with methodological and ethical issues that are irrelevant to the ‘outsider’. This can be attributed to an attempt to balance the role of ‘insider’ and the role of researcher (DeLyser, 2001; Gerrish, 1997; Kanuha, 2000). Taking on the role of the researcher can act as a barrier that separates the ‘insider’ from those in the setting they are researching. I had to be mindful that boundaries can become blurred when a relationship is present, where Gunasekara (2007) suggested that the researcher is interviewing and collecting data about colleagues. As I had previously worked with some of the participants a delicate balance existed between researcher credibility and peer accountability (Taylor, 2011) through the stages of data collection, data analysis and reporting of the findings.

“Insiders” often report difficulties they encountered in collecting data, by interview. Two reasons were attributed, the initial being that the “insider” might encounter their own reflections on the potentially personal nature of the data. This can result in a difficulty in focusing on the interview process (Kanuha, 2000). Because of this difficulty in focusing on the interview process alone during data collection, a triangulation of methods was used including non participant observation and reflective diary to inform the data analysis and findings.

The second difficulty identified by Breen (2007) regarded the process of interviewing where it can be complicated by the assumption among the participants that the researcher already knows the answers. This was particularly so in the focus group interviews with the PHNs who did infer that I was part of the palliative care team in their interviews. Some of the CNSPC focus group interviews would leave a topic where they would assume that I was familiar with the rest of the detail. For the patients I had to be conscious that my role was of researcher and not as nurse giving advice. In all these instances I needed to explore further as to what the participants were referring to. All the participants I interviewed often said “You know what I mean?” sometimes assuming that I knew what they meant and at other times appealing for some confirmation that what they said was understood or was not extraordinary. This raised two issues for me. First, the interview process was helped as I engaged with the participants I interviewed during data collection. Indeed, Garton and Copland (2010) concurred that for the best data to be obtained in interviewing, that the researcher and participants relationship should be viewed as interactions where meaning is jointly constructed by both participants. Second, is it possible ethically to ignore a request for advice or information as previously recognised by Davies and Dodd (2002)? However, it has to be acknowledged that interviewers can “lead” respondents to make responses and conclusions they might not do otherwise. As a result I was mindful to reflect on my role as researcher and any presumptions that I might carry with me that could result in difficulties with the interviews and impact on the quality of the data collected Kanuha (2000).

As researcher, I was the main data collection instrument in this qualitative approach study and so, as identified by Pereira de Melo et al (2014), it was inevitable that I had an impact on the data collected and how it was analysed. I had to consider the role I played in the research and how this influenced data collection and the analytical processes. To achieve this, and as suggested by Gelling (2014) I considered three areas. These included the manifestations of power, my stance and location as researcher and my engagement in the process of reflexivity. I attended to the “notions of power in every interaction” (Mahon &

McPherson, 2014) encountered in my research, between the different participants in the research, between myself as researcher and the participants. It was the precision and attention to detail that helped to add theoretical depth to the qualitative study. Inevitably, my stance and location as researcher was essential because I came to my study with existing beliefs and values.

Invariably, as researcher I had many of the same experiences as those in the research setting, confirming my role as “insider”. This had disadvantages because in addition I inevitably shared some of the values and perspectives of some of the participants. Gelling (2014) proposed that this could have implications for data collection and analysis but that my “insider” knowledge could also contribute to my reflexivity if managed carefully.

Hand (2003) recognised that an analysis of the context and political environment surrounding the researcher's study as a part of reflexivity added richness to a qualitative study. In the midst of this research study, Ireland was immersed in a deep financial crisis with a resultant effect on the participants and environment of the country. Reflexivity closed the door on a belief that both researcher objectivity and researcher-participant distance was paramount and it opened another one to the transparency of reality and the need to address ethical, political and epistemological concerns of research (Marcus, 1994). However, a collaborative, non-hierarchical relationship between researcher and participants was promoted where participants played an active role in the construction and validation of knowledge (Fontana, 2004).

In this chapter I discussed the research design which was guided by the philosophical underpinnings of symbolic interactionism (Blumer, 1969; Mead, 1934) and a qualitative approach to the study. Through the qualitative approach I demonstrated how the methods and sampling were employed. Participants were engaged with in their chosen environment in an effort to gather their perspective of the role of the CNSPC through focus group and semi structured interviews, and non participant observation. I then described the data analysis of the study. Thematic analysis was used in an attempt to understand the perceptions of the health care professionals, the patients and families (Boyatzis, 1998). Finally, I discussed the mechanisms used to establish rigor in this study and followed by reflexivity.

The next chapter introduces the first of three chapters on the findings and analysis. Each chapter focuses on a theme. The theme for the next chapter is Journey.

Chapter 4 Findings and Analysis: Journey

4.0 Introduction

In the previous chapter I discussed the methodology and methods used to undertake this study. The research design was guided by the philosophical underpinnings of symbolic interactionism (Blumer, 1969; Mead, 1934) using a qualitative approach.

This chapter and the following two chapters present the results of focus group interviews with the CNSPC and PHNs, and semi structured interviews with patients, family members, GPs and the representative of the NCNM. These interviews were conducted to explore the role of the CNSPC in the South of Ireland from the perspective of the participants. The themes presented in these chapters have been combined from all the interviews. Non participant observation was conducted and a reflective diary was kept to contextualise the data and this was included as part of the interpretation of the interview data.

4.1 Themes and sub-themes

The main themes and sub-themes of the findings and analysis will be presented in the following three chapters. One theme will be presented in each of the following three chapters.

The overarching themes identified were:

1. Journey as a metaphor (Chapter 4)
2. Aspects of Care (Chapter 5)
3. Role (Chapter 6)

The first theme to be discussed is journey as a metaphor with its subthemes of travelling through the journey, connection and direction.

4.2 Journey

The first theme to be discussed used the metaphor “journey”. The CNSPC in the study equated their role of accompanying the patient and family member on the palliative stage of their illness, to going on a journey. Most journeys have a purpose even if the journey in itself is the purpose. They used the journey as a mechanism to remember patients and family members and their role in the process. Using the metaphor of a journey and the

stages involved allowed the health care professionals to reflect on patients they had previously cared for. The theme “journey” was divided into three sub themes. The first sub theme was travelling through the journey meaning that the CNSPC travelled the journey with the patient and family members. The second sub theme was connection, referring to the relationships the CNSPC, health care professionals, patients and family members established on the journey. The third sub theme was direction which means receiving advice on the journey and acknowledging that there may be “bumps” encountered on the journey. The theme, sub theme and codes are demonstrated in Appendix 28.

Guidance plays a key role for the CNSPC and the metaphoric language of a journey is an important mechanism of reflecting on the stages of the palliative care journey. It helped explain the care that surrounded the patient and family member in the community. The metaphor of a journey had an action which was based around a starting point, a trajectory and an endpoint (Johnson, 1987).

The assumptions underpinning this are that the palliative care patient is also on a journey. This journey may have commenced at the time of diagnosis or recurrence where they moved to the palliative phase of the disease trajectory.

4.2.1 Travelling through the journey

This is a metaphor for the experience of travelling through the journey. Life can be described as a journey and involves travelling from one place to another. The patient’s deteriorating illness was talked about as a journey that the CNSPC travelled on with the patients, families and healthcare professionals involved in their care. Travelling through this journey was described in a number of ways. These included beginning the journey, crossing the threshold, being companion and traveller, and challenges.

Beginning the journey

The journey began for the palliative care patient with the referral to palliative care. The Report of the National Advisory Committee in Palliative Care (NACPC) DoHC (2001) pointed out that the GP has overall responsibility for the medical care of patients in the community. This results in palliative care patients being referred by their GP to the specialist palliative care services in the community. Indeed, in 2001 the DoHC recommended that palliative care should be incorporated

into the care plan of patients at an early stage in their disease. More recently a written submission to the joint committee on Health and Children, Public Hearing's on End of Life, Ryan (2013) noted that the reach of palliative care had expanded to provide palliative care at an earlier stage in the disease trajectory. Ryan (2013) recognised that this early provision of palliative care together with disease modifying treatment was applicable and tolerable to clinicians, patients and families. It was recognised that this benefitted and facilitated the transition to an ultimate focus on palliation while providing enhanced quality of care in the earlier stages of chronic disease management (Ryan, 2013).

Both GPs in the study recognised their role in referral to the palliative care services in the community. They acknowledged that they referred to and involved the CNSPC in the patients care. However, contrary to the recommendations of the DoHC (2001) and Ryan (2013), both GPs expressed concerns that the referral would be too early. From the GP A1 perspective, preparation was required before a patient was referred to palliative care. The GP was concerned for the patient and did not want to make a difficult situation worse and was interpreting the appropriate timing of the referral. Though the GP was mindful of patient concerns, the resulting implication was that this decision was not based on patient need or in providing palliative care at an earlier stage of the disease trajectory. Invariably, the GP does not want to cause distress to the patient but in addition may find it difficult to answer questions the patient may pose. The patient may be concerned at the reality of how the illness has progressed but in addition the GP may be concerned at facing this reality as well.

GP A1: But getting to that point where they do have an understanding that they do indeed have a terminal illness, you don't want to send a particular nurse too early, the person asks the question, oh, "is it like that? Are things as bad as that? " I suppose you have to have sensibility and the timing of that first visit is critical and is one that we would obviously discuss beforehand with the public health nurses and ourselves.

This theme reflected on how the decision making process may be considered. This has the potential to impact on patient need and indeed for patients at the early stage of the disease trajectory. It may ultimately affect the opportunity for the patient to receive enhanced quality of life. They may be a continuing lack of understanding of the appropriate time to refer patients to the CNSPC. Though this GP was mindful of the need

to inform the CNSPC of the pending referral, the perception continues that palliative care is associated with end of life care and not early stage of illness.

Crossing the Threshold

This relationship between the patient and the CNSPC was established by metaphorically crossing the threshold. This was by entering the patient's and family lives. This was a landmark occasion and a place of beginning for the patient and family. For many patients who were referred to the CNSPC, this was a poignant step forward into a new phase of their illness. In some instances it brought an acceptance and recognition for the patient and family that they were entering into the final stages of their life. Some patients had already overcome some notable obstacles along the way. The enormity of Palliative Care involvement was recognised by the CNSPC. They felt that the meaning of palliative care had changed over time and that patients were relieved and that it was more positive. There was a realisation for the patient that their condition was deteriorating, and there was an underpinning fear of the unknown. These assumptions were presumed through local knowledge, the association with a particular location of care and invariably palliative care association with death.

P 1: Well (chuckle), when I heard, after I getting the chemo like about, when I heard K nurses I kinda, I said "Jesus, don't tell me now, I'm going to finish up there When you'd hear K nurses are coming to you first, you'd say "Jesus, I'm not going to get better like, terminally ill or something".

There was honesty from P1 of his impression of palliative care and the resulting great sadness for him. This was another phase in P1's illness. Interestingly palliative care was associated with the hospice building even though P1 planned to continue at home. The patient had long held ideas of what this place meant and its association with not getting better. The perception of palliative care is devastation, and society's understanding is of a long and unpleasant illness. Dying is portrayed as not being good and palliative care is equated to this. Palliative care understandably equates to this sadness and loss.

Even though palliative care was perceived as devastating by the patient, the CNSPC believed that palliative care was presently viewed more positively than in the past. Though palliative care continues to be associated with death, the influence of the Irish Hospice Foundation and the All Ireland Institute (www.aiihc.org) has contributed to a more

positive image of palliative care. By influencing education, culture, and people's understanding, these organisations have tried to portray an improved quality of life associated with Palliative Care.

CNS R9 Its much more positive now, than it was going back years ago you know what I mean, where there would have been much more fear around it, we're so long on the road now,

For CNS R9, who has been visiting patients at home, the change in perception of palliative care over the intervening years was noticeable. This was echoed by all the CNSPC focus group interviews. The implication being that there was a more open and positive outlook on receiving the service of the CNSPC. This may also be attributed to an openness and reduction in collusion to the CNSPC visiting patients at home. This change can most likely be attributed to the positive portrayal by the media (Kelly, 2012) and open discussions on palliative care and its association with living (McPhail, 2000). However, this indicates a variance in the patients understanding and the CNSPC perceptions of palliative care. With this in mind, work is still necessary to improve society's perception where this includes the health care professionals. The extension of palliative care to include patients with a non-malignant illness has moved the association from cancer alone and contributed more positively to palliative care. Of course the devastation and sadness initially experienced by the patient has to be remembered.

Being companion and traveller

Journeys may be travelled alone or with a companion and much of the time we may meet people when we are travelling. The CNSPC, as companion, accompanied the patient from the time of their referral and travelled with the patient on their palliative care journey. Of significance for the CNSPC on this journey as a companion, was "knowing" the patient. When travelling on a journey the concept of "knowing" the patient is important in defining the relationship with the patient, the family members and the health care professionals and how all the relationships are intertwined.

Carper (1978) identified four fundamental patterns of knowing from an analysis of the conceptual and syntactical structure of nursing knowledge. These patterns were the science of nursing, the art of nursing, the component of a personal knowledge in nursing and the component of moral knowledge in nursing. All four patterns of knowing were deemed to be important but Carper (1978) deemed the personal knowledge as the most

difficult to master and teach. Simultaneously, Carper (1978) recognised that personal knowledge was the pattern most essential to understanding the meaning of health in terms of patient wellbeing. The interpersonal process of being companion and traveller involved interactions, relationships and transactions (Carper, 1978) between the CNSPC and the patient and family

At the focus group interview with the CNSPC, “knowing” was perceived as an important element of care, and was also acknowledged by the health care professionals and patient. In an effort to provide total care, it was necessary for CNS J1 to fully know the patient. This was happening because there was continuity of care beginning from the time of referral through the patient’s illness.

CNS J1 Because you know the patient, it’s the continuity of care, and going through the whole journey with them.

The implication of this is that knowing the patient is important to the delivery of care. Similar to Carper (1978), identifying four patterns of knowing, the CNSPC assumed that knowing was an element of total care. Time would be necessary to build this relationship for the length of the palliative care journey, as a short timeframe would not facilitate getting to know the patient and family to the same extent. Through experience, and intuition the CNSPC recognised patient need and the benefits to the delivery of care in knowing the patient through their journey.

For the patient it was the CNSPC knowing their story that assisted them to address any issues of concern. This was seen as reassuring for the patient. The CNSPC and patient had established a relationship where the CNSPC was familiar with areas of concern for the patient.

P 3. Oh ya, they talk to me, they talk about my kid like. I have a child in Q like you know what I mean. They talk about that, you know what I mean, and the care nurses they know the story as well, if there is a problem they were asking, “how are you getting on like”?

Through “knowing” the CNSPC was familiar with information that was known to only a few people. As companion and traveller, “knowing” has a confidentiality element in the relationship between the patient and CNSPC. “Knowing” facilitated the CNSPC to try to resolve issues of concern for the patient once they were familiar with them. A trust was

established through knowing and this contributed to building on the patient and CNSPC relationship. As companion and traveller, “knowing” allowed the patient to voice concerns, share information and know that someone was listening.

The healthcare professionals recognised that the CNSPC had the skill and expertise to recognise when there was a change in the patient’s condition and organised the necessary services. It can be assumed that this confidence was built upon by experience in recognising patient need when the CNSPC has sufficient time in knowing the patient.

GP B2..... and I think their confidence, I suppose, confident air that they work with, where they are able to know, night nursing is needed, and things like that and they are able to organise that, you know and I think that’s all very helpful for people,

By being companion and traveller, “knowing” facilitated the CNSPC to address and try to resolve issues for the patient as their journey progressed. Invariably, the health care professionals recognised this when additional services which contributed to patient care were organised. They had trust in how this benefited the patient and family when the CNSPC was able to anticipate patient needs and address these accordingly.

Challenges

Wallington (2010) recognised that difficulties in a relationship correspond to impediments to travel. Challenges can be encountered on all journeys and may ultimately impact on the journey. These tested the CNSPC abilities and resources in a demanding but stimulating way. Challenges can be attributable to economic realities, safety issues or cultural differences. When faced with challenges, decisions had to be made which resulted in becoming engaged in the problem, task or undertaking. The impact of this resulted in progress being difficult.

The Department of Health (1994) acknowledged the key role of the voluntary sector in the provision of health care services in Ireland. These voluntary (non-statutory) organisations have been to the forefront in Ireland in identifying and responding to the community palliative care needs (NACPC, 2001). These developments have taken place in co-operation and partnership with the statutory health service and funding is provided by the statutory service through service arrangement. Four of the five CNSPC focus groups were employed by a voluntary (non statutory) organisation.

Challenges were encountered by one of the CNSPC focus groups concerning service delivery to patients with a non malignant condition. This resulted in a difficulty for CNS E5 in the delivery of care to patients in need who did not meet the service referral criteria.

CNS E5 We would deal with it by saying; the policy of the steering Committee is we're not seeing non-malignants (patients with a non cancer diagnosis). Now, what happened to me one time when I said that and they (GP) wanted to know, they asked for the committee ring one of the member's of the steering committee to know why we couldn't see this non-malignant patient. Now that was very, I have to say, I think we dealt ok with it but I was upset, you feel a real baddy, you feel like a meany that you won't do this.

In this instance, the voluntary (non statutory) service were making the decisions concerning service delivery. This decision was in contrast to Ryan (2013) submission on end of life which suggested that palliative care is provided on the basis of need and should be an increasing component of care for all persons with life limiting condition from diagnosis to death. At the time of focus group interview these tensions were present between the decision makers and the CNSPC in deciding the referral criteria and may be attributed to lack of understanding of the role. The CNSPC recognised that they were not delivering a service to all patients who had a need.

Conflict and distress were encountered by CNS E5 especially because of an inability to change or achieve the desired result. More recently, the Clinical Strategy and Programmes in the Health Service Executive (2014) have identified the criteria for access to specialist palliative care services. This includes patients with an advanced, progressive and life limiting condition and is now embedded as part of the service provision in the service arrangement for each voluntary (non statutory) service.

Other challenges were encountered by the healthcare professionals. It was acknowledged by one of the PHN focus group interviews that increasing patient's had more complex needs. This posed a challenge for PHN K2 when a GP may decide not to refer a patient to the CNSPC service.

PHN K2 ... a lot of the GPs mightn't have palliative care involved

This suggested that the patient with specialist palliative care needs is not referred by the GP to the CNSPC. Therefore, this implied that there are some GPs who decided that they have the knowledge to care for the palliative care patient without the involvement of the CNSPC. In addition, this indicated that not all patients with palliative care needs are referred to palliative care CNSPC. However, this decision by the GP may be challenging for the PHN, where they recognise that the patient and family members may benefit from palliative care input.

4.2.2 Connection

The second sub theme connection refers to an established relationship where there is interaction between the patient, family, CNSPC and health care professionals. Davies and Oberle (1990) referred to connecting as getting in touch with the patient and family members where the nurse was entering their experience. This sub theme connection took place on a day to day basis on the journey and was described in a number of ways. These included getting to know, listening, orchestrating the progress and trust.

Getting to know

Getting to know signified that a connection was being established. It was a two way process where the CNSPC and patient and family member got to know each other. It was a mechanism to establish the building blocks to build on a relationship through the CNSPC involvement in the patient care. Four of the CNSPC focus group interviews spoke of the process involved in getting to know the patient and family members. Davies and Oberle (1990) identified one of the components of connecting, as making the connection. They suggested that it meant getting to know the other in a much deeper sense. This established a bond that enabled the conversation to progress to more difficult issues concerning the illness and where the patient was identified by CNS L3. When the connection was established, the patient could feel safe about expressing their feelings. This period spent getting to know laid the confidence and trust for the rest of the journey.

CNS L3 So you can get to know the person, initially you go in and do one or two visits they are very cautious, they haven't the trust built up but then they get to trust you, they will definitely open up more and they can tell you about their fears and Building trust is a big thing, I mean they are very frightened at the diagnosis, you can see all of that,

When the connection was established in the first few visits the patient could speak freely. To get to know the patient continuity of care was paramount, honesty and feeling that the CNSPC was trustworthy were important traits identified. Then a relationship was established that could be built upon as the illness progressed. This then provided a mechanism to discuss fears or concerns. Ultimately, getting to know was an important hallmark in establishing the relationship. The CNSPCs recognised at the focus group interviews, the process involved and the need for patients to feel trust from the outset. The implication of this theme is that consistency and continuity of care enhanced the CNSPC patient relationship in getting to know the patient.

Listening

Listening represented the way that the CNSPC took notice of the patient and family members by giving attention to what was being said and then acting on upon it so that the patient could be guided to where they wanted to go. The CNSPC had to stop talking and allow the patient to speak. To connect with the patient the CNSPC had to engage in attentive listening as described by CNS C3. Listening provided an opportunity for the CNSPC to take notice of what was being said and respond where necessary.

CNS C3..... Because attentive listening can be hard mm, sometimes, because it's a very active process. And you want to pick up on cues and so that you can explore the conversation and bring it to wherever the person may want it to go, with you.

This facilitated the patient with the opportunity to proceed with the conversation or not. Listening provided this direction. The CNSPC was trying to listen to what was being said. Listening assisted the patient in bringing the conversation to where they wanted to proceed. This was a connection at the core of the CNSPC patient relationship. It directed the relationship and where the patient was going.

Orchestrating the progress

Orchestrating the progress referred to achieving maximum effect in coordinating the patients care on their journey. There was an identified need to arrange and direct complex situations toward an ultimate goal and benefit to the patient. Orchestrating the progress involved connecting with the patient and guiding them to their goal. This

coordination of care was recognised by the CNSPC. Orchestrating the progress was recognised as an administrative role by the representative of the NCM. For the family it facilitated a smoother outcome in achieving the required goal.

Patients encountered complex journeys and orchestrating the progress provided a mechanism for CNS V5 to coordinate the journey. By planning and coordinating the elements of the patient care, CNS V5 arranged care in a way that was less threatening for the patient where there were multiple professionals involved in the care.

CNS V4 You know, so you really try to buffer them. You're trying to look at the overall picture of what it's like for them to be on the receiving end of that many professionals. I mean recently, we had a man who was under nine consultants, so we really tried to; and your hearing different information from consultants, ones that were throwing his thinking off to the left and to the right and he was left totally confused and you are trying to; Ok say "who is the person here?" that can give this man the information that he needs in order to, to continue chemo or to discontinue,

The CNSPC recognised that decisions may need to be made because of the complexities of treatment for patients. When a connection had been established with the patient the CNSPC was in a position to recognise where assistance could be directed. Multiple appointments can be overwhelming for the patient particularly where they may not be in a position to make a decision. The CNSPC in her role looked at the overall picture and arranged care in a way that was less threatening for the patient. Orchestrating the progress was a protective mechanism for patients bewildered with the enormity of information received. The CNSPC recognised the need to plan and arranged services and care appropriate to patient circumstances.

In addition to being a coordinating role, orchestrating the progress was recognised by the representative of the NCM as an administrative role in the delivery of care by the CNSPC. The CNSPC was managing the patient's appointments to avoid repeated hospital visits while being cognisant of the patient's abilities and condition. In an effort to plan the patient's care this avoided repeated hospital visits by managing the patient's care and trying to encompass a seamless service with all appointments on the one day.

NI remember a clinical nurse specialist in oncology saying to

me a long time ago, with one of her patients. I met one of her patients. She said to me you know the clinical nurse specialist is, co-ordinates all of my care, so when I have to come up to the hospital and I'm called for three different things because I have got co-morbidities, she arranges that all my appointments are on the one day. Having a very good ability to manage time, those are really important qualities.....

The implications of this theme are that the CNSPC as expert recognised that because of the patient's deteriorating condition and co-morbidities they may not have the energy for repeated hospital appointments. By orchestrating one hospital visit versus three, the CNSPC role as manager was being enacted. Through the established connection the CNSPC as the key worker was aware of the total number of appointments and in a position to plan and coordinate care.

From the family member F6 perspective, the CNSPC arranged a smooth, seamless access to hospital if required by the patient. F6 recognised that in her role the CNSPC was in a position to access admission and that the hospital respected her expertise concerning the patient needs. Because of past experiences in trying to access admission and the difficulties encountered by the patient and family at this time the GPs involvement was not sought.

F 6. I would meet them you know, or I would telephone if we have a problem for certain they are the first person I would call because we have discovered that if P3 needs to go to hospital, well the nurse, the Home Care team are the team to contact. Because there the team he will ultimately be under then in the hospital. Going via GP sends you via A& E. Unless it's late and then you have to go that way; but the other way is much more convenient.

The administrative role of the CNSPC in arranging, planning and coordinating hospital admissions for the ill patient and avoiding potential delays was highly regarded. Orchestrating the progress for the patient provided reassurance for the family member in the delivery of patient care.

Trust

Trust refers to confidence, reliance and belief in something. There was a development of trust in the connection formed by the patient and family with the CNSPC on this journey. This trust was established at the initial connection and subsequently maintained for the duration of the journey where there was a confidence in and reliance on the quality and attributes of the CNSPC. Trust was developed with the patient, PHN and GP. Work was involved in developing a trusting relationship and the need for reliability, trust and strength was required. There was a difference in how the patients and health care professionals referred to trust. Patients referred to trust from a reliance perspective while PHN and GP spoke about trust from a therapeutic perspective.

Two of the PHN focus groups and both GPs expressed a trust in the CNSPC. The therapeutic effect of trust for the PHN in the CNSPC related to pain and symptom control as confirmed by PHN M4. The CNSPC was seen as the specialist.

PHN M4 We would say his pain is not controlled, his symptoms are not; we would contact them;

The PHN valued and trusted the CNSPC skills concerning pain and symptom control and recognised the benefits and therapeutic effect this had for the patient. For the GP, trust had been established through a good working relationship with a small number of CNSPCs. GPA1 recognised this as professional trust but similarly there was a therapeutic element to the trust. GP A1 welcomed all advice and followed all direction from the CNSPC.

GP A1 They are a small number of people who we have got to know and trust over the years, and we have an extremely good working

The good working relationship between the GP and CNSPC enhanced the delivery of patient care. The GP depended upon and trusted the advice received. This type of working connection had been established over years with both parties having to work to achieve. The trusting relationship has a resulting therapeutic effect for patient care. The GP recognised how this trust has been established for them and that it has taken time. This can only result in the patient benefiting from a cohesive care network.

In contrast, there is reliance in the trust the patient encounters with CNSPC. P2 trusted the advice she received from the CNSPC when she was unwell.

P2The other day now I wasn't feeling very well.....Home Care nurse came in and she told me to take valoid (antiemetic) and I have to say, I felt grand after it.

This reliance was developed over time where the patient has a complete trust in receipt of CNSPC advice. Through the established connection the patient develops a confidence in the advice from the CNSPC. For trust to develop with the health care professionals or patient, time is necessary. In addition there has to be a firmly established connection for trust to embed.

4.2.3 Direction

The third sub theme was direction. When travelling we can meet people who provide direction and advice. But even in the best planned journey there may be bumps encountered along the way. Then there is the journey where we get lost or there are no road signs and similarly this may also be the experience of the palliative care patient. The journey metaphor allows each patient to travel along its own path, adjusting and responding to new directions (Arman et al, 2002; Byrne et al, 2002; Gibbs and Franks, 2002; Sim, 2008). As the patient moved along their palliative care journey they were accompanied by their families, the CNSPC and health care professionals on this route. Direction is described by guide, path, and destination.

Guide

To guide someone is to assist and accompany them through an unfamiliar area so they can reach their destination. The guide advises, reassures and shows the way. The CNSPC was a pioneer in showing the way to the patient and family along their palliative care journey by accompanying them, giving advice and direction as referred to in three of the CNSPC focus group interviews. This guidance was also recognised by the patient, family member and PHNs.

The patient and family member allowed the CNSPC into their lives to assist and accompany them through the illness. This was happening because of the deteriorating patient's illness and the patient had to be open to having a stranger come into their house.

As a guide, CNS D4 recognised that they were a guest as they entered the patient's and family's private world.

CNS D4..... And I think it's never to just forget that you are the guest and how intrusive we are being without being intrusive. But they allow us into such a huge part of their life; you know something that's forever remembered by the rest of their family of how this loved person dies. You know, but for us never to lose sight of, we are the visitor in this house, you know.....

This meant that the CNSPC recognised the impact of her entering into the patient's and family world as a guide. As a welcomed guide, the CNSPC recognised their role in the scenario. The CNSPC presence as guide was occurring because of the patient's deteriorating condition and the need for physical and psychological symptom support. The CNSPC was cognisant of the impact of their involvement to assist and accompany the patient and family.

The family members were reassured by the CNSPC guidance. Similar to P4, family member F5 was reassured that the CNSPC would get to the bottom of any problems. As a guide the assessment of the patient had to be undertaken before any advice can be delivered.

F5: They got to the bottom of it, didn't they (directed at patient)?

Even though the patient was experiencing symptom control issues, the families were reassured that these were being addressed by the CNSPC as they accompanied the patient on the journey. The implication for having the CNSPC to accompany the patient is that there is someone on the journey to explore and listen to the issues of concern that arise for the patient and then resolve them. With all the persons involved in the patient care, the CNSPC is the one person who is addressing the areas of concern and resolving them.

The PHN acknowledged that the CNSPC has more involvement in the patient's care. This may be attributed to the fact that the CNSPC has more time, has established a connection and relationship with the patient and will try and guide the patient through their journey.

PHN J1 The palliative care nurse has more input,

However, this implies that the PHN as a member of the Primary Care Team has less involvement in patient care than the CNSPC who is a member of the Primary Care Network. This is in variance to the model of Primary Care as referred to by the Department of Health and Children (2001) Health Strategy where primary care is centred on the needs of individuals and matches their needs with the competencies required. In contrast the primary care network is made up of additional professionals who provide therapy services required by a number of core primary care teams. The current delivery of care is contrary to health strategy as the PHN suggests that the CNSPC has more input to patient care.

This implies that the CNSPC has more involvement in the palliative stage of patient care though the PHN also has competencies to deliver. As a guide there was a suggestion that the CNSPC had more to offer, and less for the PHN to do. Indeed the PHN also has much to offer towards patient care and may feel deskilled. Griffith's et al (2007) recognised the supportive role of the district nurse that is not always recognised.

Path

A path refers to a set of actions which lead to a particular goal. Dante, the Italian poet of the middle ages found himself in the middle of a dark wood, having gone astray from "the true path" and subsequently was ready for a major change in the direction of his life. For the palliative care patient and family member they are also preparing themselves for a major change in direction as they travel on their illness path. There were choices to be made concerning which path to take and actions to be undertaken.

The CNSPC respected the patient's progress as they travelled on their path. They were particularly cognisant of how far the patient wanted to move on the path. As indicated by CNS V5, they offered the opportunity for the patient to voice whatever they felt able to speak about and at a pace they wanted to progress.

CNS V4 Well in terms of our patient is staying where there at, in terms of how much open communication they want at a given hour on a given day, and to go with them where they want to go and the time they want to go. Hoping to have open communication, whereby you give a cue for people to go further or not to go further. But you don't force people down an avenue, you go with them, and for families,

obviously it's with permission from the patient, and you say you're going with them where they want to go, where they are able to go. And sometimes you are gently trying to probe, and bring them a little bit further.....

This facilitated the patient to progress as they wished. It took a certain effort on the patient to move along the path but the CNSPC was going with them at their pace. The CNSPC was conscious not to push the pace too fast. This allows the patient to dictate the pace and discuss what they wanted to or indeed progress the conversation. On this path the CNSPC recognised that their presence was important when the patient wanted to talk and allowed the time to facilitate this.

The PHN also recognised that they had to be cognisant and mindful that the patient was on a path and consider what was right for the patient. PHN C3 acknowledged that they needed to respect the pace the patient wanted to progress.

PHN C3 Gentle with them or you know, not wanting to rush in with information, they mighten be ready, yet deep down they know it, but they are not willing to express it themselves,

The PHN recognised the need to ensure that the behaviour and manner was appropriate and not rushed. The patient set the pace. For the PHN, information was delivered appropriate to the patient situation, need and desire. The implications of this were that the patient led the way at their pace and the PHN followed at the patient's pace. The PHN acknowledged and was being mindful that the patient was on a path.

Destination

Destination refers to the purpose for which one is journeying. In the Renaissance, Hamlet (Shakespeare 1599 – 1602) instinctively described death as an undiscovered “country” from which the explorer never returned. For the patient it is the end of the road. For the families, death is a demanding time when support is required before and after. Physically, the body begins the final process of shutting down, which ends when all the physical systems cease to function. Emotionally, spiritually, and mentally, the person begins the final process of release from the body. As the destination of the journey comes closer, the patient continues to live until that shut down process ceases.

The CNS I9 perceived that palliative care was the first time that the patient was facing the reality of their illness. The patient's disease had progressed, and they had moved to a new phase in their illness. In this phase there was no cure and death was imminent. Palliative Care had arrived, the truth and genuineness of their illness was real.

CNS I9, we are the first specialty where, that the patient is likely to have met, where cure is not the intention, so it's a really very different perspective and we are coming with a very different perspective,

The patient had to face a different future and it had now become real. The CNSPC indicated that the seriousness of the illness was evident to the patient. All other specialities have dealt with curing the patient.

The patient P4 did reflect into the future and the value of having the CNSPC visiting at home. This patient recognised the seriousness of her condition. As she was looking down the road, she recognised that cure was not an option and that death was imminent.

P4. Well I'm looking down the road ahead of myself now in saying that if I was sick or extra sick or anything they are there with there advice and there help, and it's a wonderful thing to have someone coming in that's in the know about what's wrong with you and understand all the, they can talk.....

As with the beginning of the journey, the CNSPC also accompanied the patient on this stage of their journey. When a patient's condition deteriorated they are there with advice and assistance in the home. Of additional benefit was when the patient had established a connection with the CNSPC to provide the necessary directions at this time.

Believing the reality of an illness takes time for some patients and there was a process involved to reach this. As acknowledged by GP A1, the disease was present, and the patient had to become aware of it. Some people can accept this and others may not.

GP A1: obviously the person with the terminal illness has a journey they will have to travel and part of the journey is developing an awareness of the fact that they do indeed have a terminal illness and coming to an acceptance and sometimes that never happens and sometimes it does.

There was an acknowledgement by the GP that the reality of the destination takes some time to take on board. The acceptance stage is not always achieved. This journey may take time to travel, the destination may be reached or not. The acceptance of the terminal illness may be realised or not.

For healthcare professionals facing the destination could also be difficult. For PHN K2 it involved being afraid of what the patient was going to raise and being able to deal with the contents. There was a concern that the patient would raise the subject of dying and that the PHN would not be able to respond or not able to deal with it.

PHN K2 I'm not sure of the right words or the right phrases or whatever but just to get a person to open up. I'm half afraid that they are going to open up too much because as PHN H8 said you are going away then and you are leaving it to whoever is left, you know. Somebody is worried about passing on or whatever or exploring the actual dying process; there great though.

Being able to deal with dying may be a difficulty experienced by many professionals. This may emanate from lack of skills to listen and talk about death, dying, and associated personal feelings. There can be a fear and a feeling of discomfort at the conversation. These issues are raised because concerns are being voiced relating to difficult subjects for discussion.

In this chapter the first theme of the findings and analysis is presented. This theme of journey presents three subthemes of travelling through the journey, connection and direction.

In the next chapter the second theme of the findings and analysis is presented. This theme is aspects of care.

Chapter 5: Aspects of Care

5.0 Introduction

In the previous chapter, the findings and analysis concerning the theme journey were presented with the three sub-themes of travelling through the journey, connection and direction.

In this chapter I will be presenting the findings and analysis from the second theme to emerge from the interviews. This theme is called aspects of care. Palliative Care is a philosophy of care that focuses on the needs of the patient from diagnosis until death and into bereavement care for the family. In 1960, Henderson described the basic principles of nursing, to help people to perform activities that would contribute to their health or a peaceful death. Palliative care nursing involves a holistic approach to valuing all the characteristics of the patient (Sheldon, 1997). Aspects of care are a combination of palliative care, nursing care and palliative care nursing. This theme will be presented by the sub themes of team, caring and supporting. The first sub theme was team which means a group of people with diverse skills and knowledge. The second sub theme was caring which means being there, listening and willing to help. The third sub theme was supporting. The theme, sub theme and codes are demonstrated in Appendix 29.

5.1 Team

A team can be described as a group of people who have diverse but related skills and knowledge (Pritchard and Pritchard, 1994). The team come together for the purpose of directing, coordinating and developing as separate parts as well as for the total of their expertise. In palliative care, the team concept is still at its core (Loscalzo, 2008). However, there is more to an effective team than bringing a group of people together. The CNSPC in this study worked with two teams. There was the team in the community made up of the GP and PHN. Simultaneously, there was the specialist palliative care team. Each team was made up of individuals who had their own area of expertise, tradition, professional interest, working practice and professional regulatory body (Cox and James, 2004). Teamwork, team player and team challenges will now be presented.

Teamwork

Teamwork was identified as a central component of palliative care by Junger et al (2007). Firth-Cozens (1998) suggested that team working is a way to tackle the potential

fragmentation of care through a unified goal. Three paradoxes common to all healthcare teams were identified by Payne (2000). The first related to building relationships with other agencies and teams. This was particularly important for the CNSPC as they had to work beyond the palliative care team and work with the community team in an effort to provide a comprehensive service for patients. The second paradox recognised that members of the team often valued it for the mutual support it offers. This may be especially relevant where there were organisational demands and challenges placed on teams. Finally, Payne (2000) indicated that teamwork makes us think of our interactions with colleagues. Generally, we think of interactions from the professional's perspective but the patients in this study referred to the team interactions.

When two of the CNSPC focus groups discussed teamwork they referred to it from their engagement with the MDT specialist palliative care team. This referred to the combined action of the MDT in the delivery of effective and efficient palliative care to the patient and community. The CNSPC recognised that they had the benefit of the specialist palliative care team in contrast to the community services.

CNS L3 We have the advantage of coming back and meeting the multidisciplinary team, that the others haven't, and discussing it with them.

Access to the specialist palliative care team was an asset to the CNSPC in the delivery of patient care. The CNSPC was the link to the community and invariably their relationship was paramount in the transfer of information and knowledge. The CNSPC has to be assured of their role in the team because of all the disciplines involved in the provision of care. This process of care was as a result of the development of the specialist palliative care team and the combined team approach of the CNSPC with the GP and PHN in the community. This resulted in the delivery of a seamless service for the patient.

Two of the patients referred to the teamwork between the CNSPC and the specialist palliative care team which improved their quality of care. P1 was familiar with the interaction and alliance between the CNSPC and the specialist palliative care team.

P 1: Ya, they look after it, and they do their best like, they'd say "we'll ask Dr L above in K, we'll have a talk with him, or I'm meeting with him. We'd tell him what way you are like, he might have a different tablet, he might say try a different tablet like",

The combined action of the CNSPC and physician resulted in addressing the patient's symptom control problems. The patient recognised that a team approach with more than one discipline was required to address the problems encountered. From the patient's perspective, the palliative care team of CNSPC and physician worked as an entity and effective team. There was a recognition that a good working relationship existed between the CNSPC and physician. The contribution or involvement of the GP or involvement in the team was not realised by the patient.

Team Player

A team player is one who works in cooperation with others. As a team player, excellent communication skills and a clear understanding of the others' skills are necessary abilities as identified by Kedziera and Levy (1994). The team player needs to have the ability to cross organisational and professional boundaries. Both GPs recognised the CNSPC as a team player where they worked with the PHN and the palliative care team. In both instances they were seen as part of the team rather than an expert. However, as a team player the CNSPC skills as an expert complimented the PHN knowledge and information skills. GP B2 perceived that both nurses understood the other's skills in the team. This contributed to a satisfactory working relationship between the CNSPC and PHN.

GP B2. They also work, work very well with public health nurse, their roles tend to; you know some public health nurses may be there for years, you know seeing a family or whatever like that and someone else comes in, you know and I think, I think it works very well, they dovetail quite well together, each appreciates the others expertise and that. My experience is they work very well together.

Both as team player and expert the CNSPC contributed to the delivery of care to the patient and family. The PHN contributed to the total care where they were familiar with the patient and family and their needs. The contribution and knowledge each nurse brought enhanced and endorsed the others. Each nurse acknowledged the others knowledge so that they could work and harmonise as one. However, GPA1 recognised that the CNSPC as a team player was working with the support of the consultant and specialist palliative care team.

GP A1.And in fairness they are doing that with the backup of the consultant in palliative care and so there is a team there. That's good as well.

The CNSPC had the professional support of the Consultant which was important for the GP in the provision of patient care. It was perceived that the Consultant in Palliative Medicine leads and is in charge of the team and the CNSPC is a team player within this team as well. There was an acknowledgement of both the importance of the specialist palliative care team and the CNSPC position as a team player within that team.

Team Challenge

Challenges test our abilities and resources in a demanding but stimulating undertaking. As with any group of people the CNSPC and health care professionals experienced challenges in their daily team work in trying to achieve a unified organisational goal. With the onset of the economic recession and the resulting cutbacks in health services the CNSPC focus group interviews identified challenges they encountered with the PHN. This was described by CNS I9 where PHNs were not available resulting in the CNSPC having increased workload.

CNS I9 Another challenge is am, just the health service cutbacks at the minute, even though they are not effecting us directly, we are really feeling it because Public Health Nurses aren't just available, and so we are picking up pieces for everyone who needs a public health nurse so our workload has increased,

This resulted in a frustration for the CNSPC where they attended to additional duties. In addition, it had the potential to impact on the team relationship between the two nursing disciplines. Invariably, the patient experienced a lack of community professional nursing support. These situations tested the ability to deliver care to patients as well as testing the communication between both nursing groups.

Challenges were voiced at all of the PHN focus group meetings concerning their relationship with different members of the CNSPC team. Barriers to multi-professional working can be experienced where there is dominance by any one profession. This can be seen as introducing a professional hierarchy that could be counter-productive to effective team collaboration and working. This potential hierarchy was signalled by PHN

S1 of perceptions of the care delivered to patients in the community. The PHN recognised herself as part of the team but that the CNSPC did not perceive them as part of the team.

PHN S1 Because if you ever hear of people talking about he has died or you know, because they will always say how brilliant, but its fine because I would count us as part of the home care team, I don't think they see us as part of the team,

There was a perception that the CNSPC viewed palliative care as the team and did not view the community team as contributing to the patient care and service. This may be attributed to a lack of cohesiveness within the team, lack of communication and little evidence of a team approach.

Challenges were clearly identified in some of the working relationship between the PHN and CNSPC. These challenges concerned interpersonal working arrangements in the delivery of patient care. However, as indicated by PHN G7 communication and professional support was more conducive and freely available and practiced by some CNSPC colleagues than others.

PHN G7 Well we get on better with some people then we do with others and you can identify better with one person and that's how they work it out.

Because there was a better relationship with some CNSPC, the PHN was in a position to recognise the preferred working relationship. This resulted in the patient receiving a team approach and an optimal level of service. This indicated from the PHN perspective that the type of care delivered by each CNSPC varied and was dependent on personality as opposed to patient care requirements and service delivery. This may be attributed to a lack of standardised policy concerning how service operates and a lack of understanding of the others role.

5.2 Caring

Caring is dependent on a quality and type of sustained relationship and does not involve specific tasks (Seymour, 2004). The basic activities of caring are being there, listening and willing to help. The caring aspect of ministry refers to “attending physically, mentally

and emotionally to the needs of another and giving commitment to nurture, growth and healing of another” (Davies, 1995:141). The term “emotional labour” has been employed by James (1989) to account for the manner in which palliative care nurses manage emotions associated with caring. This facilitates the emotional expression that is necessary for the skill of caring that James (1989) refers to as “good” nursing. Aranda (2004) sheds further light on “emotional labour” when she considers the “cost of caring”. This sub theme describes the four elements of the ordinariness/ extraordinariness of care, being there, shared care and hidden cost of caring.

Ordinariness/Extraordinariness of care

Ordinariness of care refers to the therapeutic aspect of the nurse patient relationship, ensuring that healing occurs. Aranda (2004) referred to working in a constant balance between emphasising the ordinariness of what the palliative care nurse did and yet living to defend the need for skilled nurses in the delivery of palliative care. Ordinariness of care encapsulated doing the ordinary things but having the innate characteristic to recognise the ordinariness of the role and ultimately when a job was complete. A balance was necessary between the ordinariness of everyday encounters and extraordinariness of being in the presence of death. Extraordinariness and ordinariness are required to create stability and meaning in everyday life.

The things that made a difference that were both ordinary and extraordinary were referred to by the CNSPC. Ordinary aspects of care were sitting there, the CNSPC presence without saying a word. It was giving the patient space and permission to talk as described by CNS K2.

CNS K2Just to listen and sometimes some questions don't even need a response,,

It was building a relationship between the CNSPC and the patient, listening, where at times no response was required. It was a portrayal of the daily encounters the CNSPC had with the patient and being comfortable in the presence of the patient and providing them with an opportunity to talk. This CNSPC facilitated the patient to speak in a peaceful space in the now. There was a feeling of being safe with no barriers.

In contrast, the extraordinariness of care was described where the CNSPC was trying to understand what it was like and how it felt to be a patient, to be ill and to be dying by

putting herself “in their shoes”. For CNS M4 it was trying to recognise the uniqueness of each person. It was being present with the patient and trying to understand from their perspective during the visit.

CNS M4 I think you need to put yourself in their shoes, to try and feel what they are feeling and like for us we might go to five or six patients a day but for them, someone said it earlier they have only one chance at dying and this is their journey.

The extraordinariness of caring was viewed by the CNSPC through the unique qualities of each individual patient by trying to capture fully what it felt like. For the skilful CNSPC, this required time and immersing themselves totally in the individual experience. The CNSPC was giving herself fully to the patient. Death and dying is a unique experience for everyone and the CNSPC could not be rushed or stressed when putting themselves “in their shoes”. This required skill, a deeper level of understanding and experience gained over the years where the nurse progresses from novice to expert. There is an emotional element to the extraordinariness of caring where the CNSPC also has to practice self care.

Being there

“Being there” refers to the fact of existing or being present in a place. Having the ability to project a sense of ease, poise, or self-assurance are important elements of being there. “Being” is summarised by Duke (1998), Kellett and Mannion (1999), Wennman-Larsen and Tishelman (2002) as togetherness and partnership. It means being with someone and spending time with someone. “Being there” also had an emotional element of managing the patient, family member and one’s own emotions.

All of the health care professionals referred to “being there” with the patient and family. A family member described what it was like for them. For CNS N5, “being there” meant that they had the time to be with the patient both psychosocially and psychologically. “Being there” was possible because the CNSPC recognised that they had time but in addition the CNSPC valued being there with the patient.

CNS N5 I think we are kind of privileged really aren't we, the patientthe care...psychological and psychosocial..... A lot of the health care professionals don't get the opportunity and don't have the time to explore

those areas, one particular area whatever it maybe actually, I think a lot of the time to get the opportunity to go through the journey.

This may suggest that the CNSPC is the only person with the time to do this or that they are the only ones who get the opportunity to be with the patient. This is implying that the other professionals do not have the time to be there. The CNSPC recognised that this was important for the patient but also that they were in a privilege position to have the time to be with the patient.

The PHN perceived that the CNSPC was there with the patient and that this facilitated the patient to ask questions and receive information. "Being there" involved communication but also in this situation it meant being there for the dying patient and their family. It was recognised that this involved time and there was an understanding that the CNSPC had this time. "Being there" was perceived by the PHN as different to the normal delivery of care.

PHN D4:whereas if there have somebody there to talk to them they can develop a relationship, they can ask certain questions and gain more information,

The implication from the PHNs perspective was that the CNSPC was establishing a relationship with the patient. Through the CNSPC presence, communication and relationship building was being facilitated. The PHN recognised that they did not develop the same relationship with the patient. Through the CNSPC presence difficult questions could be addressed. The PHNs did not visualise themselves as "being there". They did not recognise that they have similar skills contrary to Griffiths et al (2007) suggestion that the district nurse also provided supportive care. The implication was that the PHN would not be able to provide and deliver on such a skill when they are present or that by being there that they were not in a position to listen or to respond.

From the GPs perspective "being there" involved being present, putting aside time for each visit and not being rushed. The GP perceived it involved sitting down and having a cup of tea, an opportunity to talk and discuss a situation in a relaxed environment.

GP B2, they just don't breeze in or breeze out; they sit down, have a cup of tea or whatever like that, talk to family and patient and

that, you know, and they I suppose, can discover areas that patients don't discuss with other people.

There was a perception that in “being there”, there was a contentedness, an acceptance of the CNSPC presence. The patient and family were at ease and confident and comfortable and reassured at discussing issues not discussed otherwise. The implication was that the CNSPC presence facilitated openness. The assumptions were that it was the CNSPC role to sit down, and be a listening ear. A positive assumption was that the patient and family recognised that this was someone they could discuss areas of concern with or make decisions concerning the future. By “being there” with a “cup of tea” it was all contributing to a calming situation.

From F6 perspective “being there”, meant that the CNSPC was available when the family member wanted to discuss issues of concern. There was an assurance that the CNSPC was there and would answer the necessary questions.

F 6 And even if you had a query, like you ring them up if you have any worries you are not going to, you are not bothering somebody, you know they are great for advice, you know.

The CNSPC was viewed as a key worker to address all concerns or worries. A trusting relationship had been established. There was a confidence in the CNSPC. The family member was assured that the CNSPC would be able to provide confidence and assistance with any queries and worries.

Shared Care

A key recommendation of the NACPC was the concept that “shared care” for patients receiving palliative care in the community would be promoted (DoHC, 2001). This was promoted to avoid duplication of services and to ensure that patients were not overcrowded in their own homes (DoHC, 2001). The NACPC perceived that the role of the specialist palliative care nurse frequently overlapped with that of the PHN (DoHC, 2001). Both sets of nursing skills are being brought together to agree the patient's care in a shared care approach. One of the CNSPC focus groups practiced shared care with their community colleagues in the delivery of care to their patients. In contrast two of the PHN focus group interviews described the difficulties encountered in the delivery of patient care.

At interview only one of the CNSPC focus groups indicated that shared care was in place with the PHNs as recommended by the NACPC (2001). Shared care benefitted the delivery of care where the CNSPC and PHNs came together with their joint skills and areas of expertise. This enhanced team relationship in the provision of patient care.

CNS R9 Our initial contact then with our patient together with our public health nurse doing a joint assessment together, from the general and the palliative care specialty. And from there then you are formulating a plan based on what you find and what needs addressing, you formulate a plan between yourself and your colleague to organise our visits so that we are not visiting at the same time, that we are spreading it out. And that we are bringing the plan organised, the method of care to our patient, rather than being ad hoc, because for the good of the patient and we work together.....

This plan of care appeared to provide a cohesive service to patients in this area. Invariably, it encouraged a working relationship with the PHN service with the patient as the central focus. From its inception, the service had developed with this working relationship. The implications were that this method and a shared plan of care worked for this team and it enhanced the delivery of patient care. In addition, it avoided replication of visits. Of further benefit was its contribution to influencing the PHN knowledge in palliative care because of the continued working relationship with the CNSPC. The implication of shared care was that one nurse was not taking over care from another. Both had skills and expertise to bring to the patient. The patient benefitted from a shared seamless service. In addition, the community nurses were not deskilled in the care of the palliative and terminally ill patient and were gaining skills in palliative and end of life care. Ultimately, the patient was benefitting from the care and skills of both nurses delivered by a collaborative service.

In contrast, PHN R9 experienced difficulty in trying to engage with the CNSPC in sharing the patient's nursing care needs. This situation had arisen because the patient had nursing needs. The PHN required assistance and the CNSPC was not in a position to assist.

PHN R9 There adamant because I had a personal care situation where I needed help and the two of us were there and I asked her for help and she refused.

This has resulted in a lack of a shared approach in the delivery of care to the patient. Personal care is a basic need and the CNSPC was unable to provide professional assistance to their colleague. This resulted in a breakdown of communication between both nurses. There was a disappointment voiced by the PHN.

Hidden cost of caring

The hidden cost of caring refers to the psychological impact of the intensity of caring. Aranda (2004) refers to the daily experiences of palliative care nurses where they deal with people who are distressed, in pain and struggling with questions of meaning. The work of the palliative care nurse is hidden from view from a social perspective where the general public have both a fascination with death and avoidance of its proximity (Aranda, 2004). The CNSPC deals with the suffering on a daily basis where they require a combination of skills to care for each individual patient. Skills such as clinical knowledge, clinical expertise and human compassion were all identified by Aranda (2004).

This hidden cost of caring had an impact on the functioning of the CNSPC. The role of the CNSPC had changed over the years and this impacted on CNS M4 contribution to end of life care. Nursing care at the end of life was recognised by CNS M4 to be highly important but was not now possible to deliver on. The difficulty in delivering on end of life care was problematic for this CNSPC. There was an associated sadness experienced by CNS M4 that they were not now able to deliver on this.

CNS M4 The other thing I find a bit of a challenge; there is nobody doing with end of life, like, end, end of life care, like the last 24hrs; that we haven't time, you know we go in put up a driver, but then we have to leave, whereas before we would be able to stay there for long periods, and go back and go back and do all that but that's a luxury now. Like I love (emphasised), I, just to be able to do that again,

The difficulties associated with spending time with the patient at the end of life were attributed to lack of time. This was in contradiction to the previous earlier suggestions concerning the availability of lots of time to deliver holistic care. It appeared that end of

life care together with the provision of direct nursing care had previously been delivered in the past. The importance of direct nursing care and end of life care is significant. This was a change in role following the implementation of the CNSPC and this had changed the delivery of care.

Two of the CNSPC focus groups referred to mechanisms to protect themselves. They tried not to give everything of themselves in regards to their personal life. They were trying to maintain a professional relationship and a distance. This was a protective mechanism they had built up to preserve themselves from the hidden cost of caring.

CNS F6 It's difficult, they usually start, people ask you where are you from; and they kind of worm their way in, you give a little bit but you kind of hold a lot. You wouldn't be selling your soul.

There was a balance, between being the CNSPC and opening up their inner most feelings. They were building a relationship from the outset and establishing trust but in the process trying to give some information of themselves and maintain a private element to their life. The CNSPC wanted to give a certain amount of themselves but also needed to maintain a protective layer. The CNSPC was trying to employ an air of professionalism and a balancing act of giving a certain amount of themselves to establish a relationship with the patient. This was a fine balancing act of professionalism, relationship building and minding oneself. There was an acknowledgment that they needed to protect themselves, and that they could be vulnerable.

5.3 Supporting

Palliative Care provides support and encouragement. It is pivotal and vital to the delivery of patient care and to the value of the organisation. Support was a central feature in the Macmillan study of nurses' accounts in their patient care role (Skilbeck and Seymour, 2002). The (Skilbeck & Seymour, 2002) study showed that support and its provision had dimensions that related to both the nurse – patient relationship and to aspects of team organisation and interaction. The sub theme supporting will be presented through social support and triangle of care.

Social support

Cobb (1976) described social support as information leading individuals to believe that they were cared for, valued and belonged to a network of communication. Different types of social support have been identified by Payne and Seymour (2004). These include informational, tangible, emotional, and validatory support (Payne and Seymour, 2004). These related to the provision of knowledge relevant to the situation, activities perceived helpful, perceived availability of thoughtful, caring individuals who can share thoughts and feelings and when the appropriateness of a person's beliefs and feelings are acknowledged. Patient's and family members acknowledged the social support provided by the CNSPC.

From P2 perspective there was a feeling of security and socially supported when in the care of the CNSPC. P2 perceived that the CNSPC was a caring and thoughtful individual who was available for the patient and family. P2 felt safe in this caring environment. The patient had complete confidence in the care she and her family were receiving.

P 2. I feel safe in their hands; I feel very, very safe in their hands and there after being so good to me and good to my family and that means everything like. That means everything, you know.

The patient was experiencing confidence in the social support provided. The patient was protective and concerned for her family and was confident in the care and social support received. This suggests that the relationship the patient had with the CNSPC offered her complete confidence and that there was reliance in the support and care received. The experience of the CNSPC involvement, afforded the patient this security. Each patient was experiencing a myriad of feelings and concerns through their illness trajectory. To receive support and feel safe and secure was most reassuring.

Similarly, family members felt socially supported through the involvement of the CNSPC in their care. For F6, it was the security in knowing that the CNSPC would answer the phone and provide the knowledge relevant to the situation.

F 6. I think so, yes, it takes the stress out of it, it can be stressful. I can ring, well they are always on the end of the phone, they are extremely good and they know P3 and they come or you know or they arrange whatever is necessary. So they are on the ball.

There was someone to acknowledge their situation and there was a confidence and security that they were being supported. There was somebody to talk and listen. This was supportive through the knowledge that someone would deal with the concerns and issues if the patient became unwell. This contributed to a less stressful situation for both the patient and family member. There was confidence in the system. Family members wanted to be supported, they wanted to talk to someone who knew the patient or knew what to do. Support was provided from being available, being at the end of a telephone line. The family in their role as caregiver needed to feel supported through the disease trajectory. Where a family member was socially supported, this invariably resulted in a positive impact on the delivery of patient care.

Triangle of care

The triangle of care means that there was a therapeutic alliance between the patient, and health care professionals. This alliance promoted and supported communication as well as sustaining wellbeing and promoting safety. This therapeutic alliance was an enclosed angle of care. As a health care professional, the CNSPC was pivotal and facilitated its operation. The sides of the triangle represent in magnitude and direction the forces of partnership for patient care. The patient was located in the centre of the triangle. Each health care professional had a different angle but also had different elements of care to offer. Three of the CNSPC focus group interviews referred to the triangle of care.

The CNSPC suggested the supportive element was a large part of the role in promoting the therapeutic alliance. This underpinned the CNSPC role. The CNSPC suggested that they co-ordinated and mediated all the therapeutic elements of care. This was one of the reasons the CNSPC viewed themselves as dominant in the triangle of care. For CNS K2, they were another circle in the triangle of carers.

CNS K2 We're another triangle in the circle of all the carers, and in some cases we may have a more dominant role. But generally that's where we fit in. I think support is a huge element of our role, support of the family, the other teams.

The CNSPC had a supportive role in this triangle to support carers, patient and the health care professionals. As intermediary in the triangle of care, the CNSPC was the link between the patient, family member and health care professionals. There was a

recognised need by the CNSPC to support the therapeutic alliance in the triangle of care. This may have been occurring because of the CNSPC connection between the patient and GP concerning symptom control issues and to the PHN concerning nursing care. As the intermediary and dominant link this may imply that the CNSPC was a primary care member rather than in an advisory role to the PHN. However, it is the PHN who is a member of the primary care team. However, with the CNSPC position in the triangle of care, they were contributing to the provision of a seamless service with the transfer of information from palliative care to the community.

For GP B2, the hospital services were also included in the triangle of care where the CNSPC was the centre of the link within the primary and hospital services. This followed the patient's pathway, linking services together and advancing admission where necessary in a crisis situation.

GP B2..... I think they are also a kind of a link between secondary, the hospital care and ourselves, like in the sense if someone, you know people can be in and out of hospital whatever like that. They are up and down to the chemotherapy day ward or whatever, or sometimes they will need to be admitted for a crisis in palliative care or whatever like that. So there is a link then, they make a link then, they make a link between the primary and you know.....

This was happening to enhance patient care. It was reassuring for the GP where an ill patient received the appropriate care when necessary. The triangle was linking primary, secondary and specialist all in an effort to enhance patient care. The GP was also recognising that a link was required between services and the CNSPC was embedded as the link key worker role. Embedded within the triangle of care, the GP had access to the hospital and palliative care services. They GP recognised the central role of the CNSPC in the link from one service to another and how the process could be seamless and focused on patient care at all times.

In this chapter, the second theme of the findings and analysis is presented. This theme of aspects of care presents three subthemes of team, caring and supporting.

In the next chapter the third and final theme of the findings and analysis is presented. This theme is role.

Chapter 6 Role

6.0 Introduction

The previous chapter presented the findings and analysis on the theme aspects of care. A number of sub themes were explored. These included team, caring and supporting.

The third and final theme from the findings and analysis of the interviews was role. Within this thesis, role refers to an explicit description of the contribution that a person makes to their team. The theoretical framework of role theory formed the approach for this study, where the concept of roles can be described as a set of connected behaviours, rights, obligations, beliefs and norms in a social situation. Roles allude to clusters of functions that come to be expected of persons within positions in which they occupy in the organisations for whom they work (Benne & Bennis, 1959). The concept of role explains how organisations function. Indeed, Goode in 1960 attempted to develop role theory by suggesting that societal structure are made up of roles. However, roles are impersonal and do not characterise the persons who hold them. The significance of role for the CNSPC related to the function and position they held in their respective teams. Role was attributed to all elements of their daily work. Appendix 30 demonstrates this theme together with its subthemes and codes that emerged during the analysis. Within the overarching theme of role the subthemes of role structure, role model and expressive role were identified.

6.1 Role structure

Role structure refers to a set of defined roles and interrelationships among those roles that the team members defined and accepted. As a framework, role theory related to the properties of the organisation and the members within the team. Role structures emerged as a result of role episodes. Role structure defined the role of the CNSPC. There was an interrelationship between the different elements of role structure. This sub theme describes the elements of expected role, enacted role and role ambiguity.

Expected Role

Expected role for the CNSPC referred to what other members of the team, health care professionals, patients and families expected the CNSPC to do. Meanwhile, many versions of role theory believed that expectation's learned through experience were the

major generators of role (Biddle, 1986). The CNSPC recognised that the expected role commenced with patient care and extended to family care. In this study role theory provided a useful framework to describe role perception. The health care professionals identified from their perspectives what they recognised as the expected role of the CNSPC. Involvement in pain and symptom management, counseling and providing support were all identified as elements of the expected role.

The representative of the NCNM personal understanding of the CNSPC role and knowledge was that the role focus was on symptom management. The CNSPC was engaged in assessment of a range of symptoms and in delivering counseling.

N. they could undertake a full assessment, and then maybe, there may be so many symptoms whether it is nausea or whether it is constipation or whether it is pain or fatigue we know is the worse thing, where you need to offer counselling...

The expected role was linked specifically with palliative care and its clinical focus on pain and symptom control. Similarly, the psychological aspect of the CNSPC role was the expected role identified by PHN L3.

PHN L3 I see them too as like in a counselling role, you know they go out and visit and they might maybe spend an hour or two if the client wants to discuss.

The communication element of the role and what it constituted was highlighted. The need to listen and spend time with the patient, in order to allow them discuss any concerns was recognised as elements of the expected role. In an effort to ensure an effective visit, the time demands of the expected role were highlighted. In addition, this signified the time requirements of the patient and family members. The expected role also highlighted that the patient chose to discuss issues of concern with the CNSPC in contrast to discussing these with other health care professionals. This may be attributed to fears that patients may raise issues that other healthcare professionals cannot respond to. It was suggested the CNSPC is best placed to provide this service.

The supportive element of the CNSPC role was recognised by PHN M4

PHN M4 Being a support for the family too, that would be the role as well;

There was a recognition that the care extended past the patient to the family and that the family needed to be supported so that they could be in a position to care for the patient. This involved giving assistance, approval, comfort and encouragement to the family as they cared for the patient. The supportive needs of families were acknowledged and that the CNSPC was best placed and had the skill to address this need. There was recognition that each patient and family were one entity and that the CNSPC was appropriately placed to address the total care. For the patient the expected role focused on medication management.

The expected role of the CNSPC described by P2 was to ensure that medications were taken as prescribed. The aim was to empower the patient so that they were knowledgeable about their medication. It was also to ensure that they were aware of why they were taking them and meanwhile the patient would feel in control and confident about their medications.

P 2. And organise me tablets, boxes and all for me, put the days on them because they were all mixed up. Home Care Nurse took the box and put from Monday to Sunday, all the days on it, the way I would know what I would be taking and my mid day tablets and my night tablets. She showed me how to do the box; she used to do me box and all for me because I didn't know how to do it myself to be honest with you.

The CNSPC undertook appropriate measures to ensure adequate medication administration resulting in the patient recognising the importance and significance of medication management and control.

The representative of the NCNM, PHN and patient identified what they recognised as the expected role. However development needs of the role were also identified by the GP and PHN. Following reflection on current practice, GP A1 considered how the CNSPC could engage within the primary care team meeting with the aim being to discuss patient management. GP A1 questioned the current actions and practice and how these could be improved upon.

GP A1: Exactly, as it is, as it is the palliative care nurses work closely with the public health nurses as it is and so this could be another forum (Primary Care Team Meeting) where they can discuss management along

with the general practitioners, you know.

Through reflection on practice, the GP considered alternative patterns of working that would enhance patient management and bring the primary care team together. Similarly, PHN P7 was mindful of the primary care team members and how they worked together and through reflection identified how the CNSPC involvement in the primary care team could benefit patient care.

PHN P7 Well you know, she could attend meetings, about patient care. The GP would be there, the public health nurse, the social worker, OT, you know all the relevant professions that would be involved, palliative care would be there, so like the input of all those professionals would add to the patient care at the end of the day, she would ya,

By immersing themselves within the team meetings, the PHN considered their knowledge and experience to understand the CNSPC involvement and how patient care could be improved. This corroborated with the recommendations of the Primary Care Strategy (DoHC, 2001a) as well as the recently launched policy by the HSE (2014) on the development of Community Healthcare Organisations. These provide a framework for the governance and organisation of all Community Healthcare Services. An essential theme underlying the recommendation of this report (HSE, 2014) was the importance of developing a new integrated model of care where all services worked together in a well co-ordinated way around the assessed needs of the person. The CNSPC participation in the primary care team meetings would achieve this. The different norms of the CNSPC, Healthcare Professionals, patient and family referred to in the expected role were assembled into sets of expectations and applied to the situation within the social unit, where the expectations then define the norms. Role theory then joined the selection of norms and began the process in developing the formation of the role (Sumner, 1906).

Enacted Role

Enacted role refers to what the individual actually does in the role. The enacted role, in turn, influences future expectations of the team. The factors identified by Lindsmith and Strauss (1968) including identification of self and behaviour in given situations facilitated the identification of role enactment where one of the characteristics of role theory concerned social behaviour. The CNSPC focus group interviews indicated what they did by distinguishing themselves from other nurses in the community, by recognising and

discerning the different signs or characteristics. There was general consensus by all of the CNSPC focus group interviews that the role was focused and specialist. This was in contrast to other nurses in the community who had a broad scope where they cared for the newborn to the older person.

The CNSPC practice focus was highly skilled in palliative care.

CNS R9 I would see as well that the public health nurse would cover a wide variety of things, we're very clear with one specific area and we can focus on that, you know. As opposed to other disciplines that cover so many varied areas, from childcare to geriatrics you know, and our role is more specific.

The enacted role recognised that there was a difference in practice and nursing focus between the CNSPC and PHN where the PHN was a generalist and the CNSPC a specialist. As generalist the PHN did not have the same level of knowledge pertaining to palliative care or indeed the level of time necessary to deliver care. This implied that the CNSPC was the specialist and concentrated on palliative care and that they had considerable more time to dedicate to palliative patient care than the PHN who covered all areas of care. The CNSPC had a different level of knowledge and education. This was a specialist knowledge compared to other nurses working in the community.

CNS I9 and so we have specialist knowledge, and that is where our focus is really tying in. We have very specific specialist knowledge, that other nurses in the community have much broader knowledge.

The enacted role had developed through both role and specialisation development. This was recognising the elements associated with a specialist versus generalist role and the difference between both nurses from the CNSPC perspective. The CNSPC recognised that the PHN was not a specialist and that the PHN did not have the same time or skill to deliver palliative care. The importance of how the CNS behaved in the role and influenced others both internally and externally to the organisation was signalled by Brooks et al (2007) and in practice as a specialist the CNSPC was expected to spread this knowledge to others in the community as part of her education and training role.

However, CNS O6 recognised that the PHN was the primary care giver and as specialist the CNSPC was complementary to the primary care givers. This supports the Primary Care Strategy (DoHC, 2001a) where the PHN is a member of the primary care team and the CNSPC as a member of the Primary Care Network.

CNS O6 I suppose we're probably, you would kind of say we're kind of complementary I suppose to public health, really. The public health nurse would sort of be the primary, the primary role really. We would be complementary to those and I suppose because we are specialised in symptom control

The CNSPC specialist role was integral to the primary care giver role because each nurse discipline emphasised the qualities of the other. Though the CNSPC had a specialist role there needed to be recognition of the contribution and qualities of each role and how the specialist could contribute and complement the generalist role. By combining skills they could enhance the provision of care to the patient.

Role Ambiguity

Role ambiguity arises when the role is unclear. This situation can arise when there is lack of clarity of one's role. It can stem from poor job descriptions, vague instructions from a manager or unclear cues from co-workers. Role ambiguity was attributed to an organisations size and complexity as well as rapid organisational change by Kahn et al (1964).

Role ambiguity was highlighted by the representative of the NCM, the CNSPC and the PHN. The representative of the NCM highlighted that service need signified scope of practice for the CNSPC. Where there was role ambiguity, the CNSPC ended up providing a service that the patient may otherwise not receive.

N..... .. the service need will determine the scope of practice and the caseload for the clinical nurse specialist in the community depending on what else is available or not because often clinical nurse specialists fill in the gap. ..

This was attributed to lack of consistency or standardisation, economic circumstances and other services not being available. The implication of role ambiguity was that there was

no standard practice and the CNSPC role was not defined. Role ambiguity was confirmed by CNS V4 where it was suggested that the role was endless.

CNS V4 Like the brief is endless, if you were to talk about role and support you could have us doing anything sometimes, and nobody else fulfils that role.....

Where there was a lack of role clarity the CNSPC undertook a vast range of work that extended beyond the role. This resulted in the CNSPC undertaking functions that were not part of the role but there was no one else to fulfil these. The implication of role ambiguity for the CNSPC was that additional roles were taken on. This resulted in frustration and a sense of exasperation that the CNSPC completed unfilled roles. The resultant effects of such role ambiguity were heralded by Rizzo et al (1970) as increased tension, anxiety, fear and hostility, decreased job satisfaction, and loss of self-confidence, often with lower productivity.

Role ambiguity was also experienced by the PHN, where there was lack of certainty for the PHN concerning the CNSPC role. This was attributed to blurring of boundaries and lack of coordinated care.

PHN I9 I suppose that's it again like, the boundaries can be a bit blurred, again I would see them as very much a support and if you, if a person needs a syringe driver, but if you can co-ordinate our visits I think it works very well...

This implies that there was lack of clarity about expected behaviours, and uncertainty about the expectations, behaviours and consequences associated with a particular role. With uncertainty, blurring of boundaries developed resulting in a need for coordinated patient care. This may be attributed to lack of decision making at role development where there was a need to clarify roles. As with the CNSPC this may potentially result in tension between nurses with frustration around boundaries. Role ambiguity led to frustration and conflict (Redekopp, 1997) with a potential impact on behaviours.

In order to address role ambiguity, the representative of the NCM recognised the need for the CNSPC to understand and be able to articulate and define their role within the team so that each member of the MDT understood the role.

N. unless we learn to articulate what it is we do and how we do it, and what the interventions are and whilst that is difficult in the context of the multidisciplinary team,

There was a need for the CNSPC to clarify their role, how it was performed and the interventions that were involved. Role clarity is particularly important when decisions are being reached in the MDT. If the CNSPC is unable to articulate their role it is difficult for the MDT to understand the role and this becomes an issue when decision making within the team is being engaged upon and this accentuates role ambiguity.

6.2 Role Model

Role model refers to a person whose behaviour, example, or success is or can be emulated by others. In addition, role models play an important part in shaping other identities (Gray and Smith, 2000; Quinn and Hughes, 2007; Royal College of Nursing (RCN), 2007; Nursing and Midwifery Council, 2008a). A role model is someone who is looked up to and who others aspire to be like. A competency long recognised as inherent in CNSPC practice is that of professional development role model. The importance of role modelling was highlighted by Bandura (1977) and reflecting on role theory and social behaviour, most human behaviour is learned from observing others, where ideas are formed of how new behaviours are performed. The CNSPC demonstrates desirable practice behaviours for others to emulate. Indeed, whether consulting, teaching, or conducting research, the CNSPC as role model demonstrates professional behaviours for staff. This sub theme describes three elements of professional development, specialist knowledge, audit and research.

Professional Development

Professional development refers to a process of improving and increasing the capabilities of staff through access to education and training opportunities. At an individual level the CNSPC had to be equipped with the theory and technical competence essential for practice. All the CNSPC recognised their need for continuous professional development.

CNS G7 We have to keep skilled, updated and aware of it.

Education and training were one of the five core concepts of the CNSPC (NCNM 2008). This indicated that each CNSPC was responsible for their continuing professional

development, including formal and informal educational activities, and thereby ensuring sustained clinical credibility among nursing, midwifery, medical and paramedical colleagues (NCNM, 2008).

Professional development was available, though all CNSPC acknowledged challenges they encountered in attending continuous professional development. Time appeared to be an obstacle in attending education programmes though all CNSPC were mindful of their needs to keep updated. Difficulties were encountered by the CNSPC when it came to deciding how to fit the continuous professional development with the clinical caseload.

CNS K2 They will often be education sessions, but sometimes then they will be an audit meeting or the journal club on a Friday which is even more difficult to get to, because it's in the middle of a day, in between visits, and its just too hard, and especially on a Friday, because the traffic is bad as well. So education sessions and journal clubs while they should be an ongoing part of our role, they become an additional extra, if you can get in.

Though challenging to maintain continuous professional development, it is a requirement of CNSPC practice (NCNM, 2008). Both the representative of the NCNM and GP recognised a further area of professional development for the CNSPC in the area of nurse prescribing. It was perceived as an important and positive development for the role of CNSPC by the GP and representative of the NCNM. The CNSPC focus group interviews did not refer to nurse prescribing.

GP A1: I think one of the things I would like to see the palliative care nurse do is that within their scope of practice that they would be able to prescribe medications themselves. Whereas I think it, it would be very important for the development of the role of the palliative care nurse as a clinical nurse specialist, within their scope of practice to be able to prescribe...

Nurse prescribing would expand the CNSPC role within the scope of practice, enhancing skills, competence and knowledge as a nurse practitioner. Through the CNS' competencies, this would be a mechanism to demonstrate continuous professional development by the CNSPC and therefore increasing their knowledge. Invariably, this would assist in the development of collaborative practice agreement with the GP and improving relationship building. This was recognised as having a positive impact and

being of benefit to patient care with additional skills. In addition this would increase the knowledge and enhance the competence of the CNSPC.

Specialist Knowledge

Specialist knowledge refers to a person who specialises in or devotes themselves to a particular area or activity. The specialist performs skilfully and has expert knowledge in a particular field. For the CNSPC this specialist knowledge was in the area of specialist palliative care. Being a role model required the CNSPC to maintain a level of specialist knowledge. Durbin and Tomlinson (2014) indicated that individuals typically identify with positive role models who can offer information, performance standards and skill expertise. The GP, PHN and Representative of the NCNM recognised the specialist knowledge of the CNSPC through their expertise.

The expert role of the CNSPC was recognised from the outset by PHN N5 through the delivery of care. The behaviour from the role model is essential and ultimately how the learner interprets this specialist knowledge is paramount (Vinales, 2015). The CNSPC was portrayed as being knowledgeable and skilful in the total care of the patient.

PHN N5 I suppose they meet the client, and they look up the prescriptions they have and they draw up a plan and a prescription plan around the management of the symptom. They call back you know to assess how the symptoms are being managed,

This implied that the patient was receiving appropriate management. As a close role model, the CNSPC interacted frequently and directly with the GP and PHN and provided guidance on performance, management style and feedback (Durbin and Tomlinson, 2014). In addition, in a learning environment the GP and PHN can learn from the CNSPC as a role model whether the learning is planned, intended, unplanned or unintended (Gaberson and Oermann, 2010). As an expert the CNSPC was influencing the GPs prescribing. The PHN was also benefitting and learning about the appropriate patient medication management. This demonstrates a cohesive, all encompassing level of patient care delivered throughout by the expert. While there are other disciplines also involved in the patient's care the PHN was acknowledging the expert role of the CNSPC. In this instance the PHN valued the CNSPC role and engagement with the patient. They recognised the skills necessary to deliver on this level of total care. The five core

concepts of the CNSPC role were identified by the representative of the NCNM where the clinical focus was recognised as the most important.

N. Obviously the key functions, the most important key function, obviously we have the five core concepts, but the key function of those five core concepts is the clinical role is probably one of the most important whereby the CNS in palliative care has a caseload of patients and is able to manage that caseload of patient within their scope of practice.

To be an expert the CNSPC role includes the five core concepts and practice within their scope of practice. The defined key functions of CNSPC determine the expert role and indicated what the expert role consisted of. It was perceived by the GP that the CNSPC was both knowledgeable and skilful in administration and management of medication. The CNSPC was known as an expert and the healthcare professionals valued the input and role, skill and contribution to patient management.

Audit & Research

Audit is designed and conducted to produce information to inform delivery of best care. Research attempts to produce new knowledge about the health service. It aims to generate hypotheses as well as studies that aim to test them. Audit can be used by the health care services to address current practice and contribute to the evaluations of improvements in the quality of patient care. It was necessary for all health care professionals to keep up to date with relevant current research and to ensure the delivery of evidence based practice and research utilisation relating to palliative care. All of the CNSPC focus groups referred to the area of audit and research being the least developed as indicated by CNS C3. Lack of time was attributed to not participating in research and audit by all CNSPC participants.

CNS C3And mm, I suppose the research and development is the one area I would find for my perspective that I probably would do the least because, you know, I suppose work commitments. Its part of the role I have least developed.

However, one of the five core concepts of the CNS role (NCNM, 2008) is audit and research. The NCNM (2008) indicated that audit of current nursing practice and evaluation improvements in the quality of patient care were essential requirements of the

CNS role. Relevant current research ensures evidence – based practice and research utilisation is up to date (NCNM, 2008). The representative of NCNM acknowledged that the CNSPC was scared of research and audit.

N. Ya, a lot of clinical nurse specialists get very scared, frightened by research and auditYou know even something simple like, there is probably a list of ten interventions, maybe fifteen, that they do everyday for patients, so you keep a record of it and you follow up and you find out, did your intervention actually have an impact, and if so can you demonstrate it.

Though audit and research was part of the role of the CNSPC, few demonstrated characteristics of the role model in this area.

6.3 Expressive Role

Expressive roles refer to the way of participating in social relationships. Coverman (1989) argued that time and energy is exhausted by multiple role involvements. Persons in expressive roles tend to pay attention to how everyone is getting along by managing conflict, soothing hurt feelings, encouraging good humour, and taking care of things that contribute to the feelings of the particular social group. These emotions, along with the increased probability of conflicting role obligations, are suggested to lead to role strain and diminished psychological well-being (Barnett and Baruch, 1985; Goode, 1960). The CNSPC was centrefold in participating in social relationships. This sub theme describes three elements of affect attunement, role conflict and role strain.

Affect Attunement

Affective attunement refers to the interpersonal contact which is essential to human relationship. Rushton et al (2013) recognised that moral distress was a pervasive reality of palliative care practice. They described a framework where clinicians were expected to respond to the patient's suffering based on four factors. These included empathy or emotional attunement, perspective taking or cognitive attunement, memory or personal experience and moral sensitivity or ethical attunement (Rushton et al, 2013). This interpersonal contact by the CNSPC was required when the patient's condition was declining. Through the interpersonal contact, both the patients and family needs and losses were recognised. The need to recognise and pay attention to personal family

circumstances was paramount in the contact. All CNSPC experienced situations where they had to be attuned to participants needs. Empathy, an affective process was aroused for CNS G7 in her relationship with the mother's grief.

CNS G7 The loss of their role is huge, like a mother is totally, for a mother to sit there and her children come in from school, and she can't make them dinner, that's a grief.

At this time, care would have been provided by CNS G7 with integrity. Resilience would be called upon in the face of the grief rather than becoming overwhelmed with the situation. Simultaneously, there was a need to remain personally and professionally grounded.

Role conflict

Role conflict occurs when people are confronted with incompatible role expectations in the various social statuses they occupy. When role conflict is considered from a role theory point of view, Rizzo et al (1970) suggests that when the behaviours expected are inconsistent they result in stress, dissatisfaction, and performing less effectively than if the expectations imposed did not conflict. Role conflict can be for varying periods of time, and it can also be connected to situational experiences. The effects of role conflict can be related to individual personality characteristics, interpersonal relations and organisational issues. Role conflict resulted from a discrepancy between the role requirements and the person's personal values, attitudes and needs. When potent expectations were contradictory, the CNSPC and PHN found themselves in role conflict (Benne & Bennis, 1959). Roles were found to be challenging when contradictory messages were given out. For the PHN B2 there was apparent conflict in the delivery of care where there was a variance in the understanding of the others role. The CNSPC practice and connection had changed from previous times. The lack of contact was impounding the situation.

PHN B2 Before I remember when I started first, we had a great link you know with the Home Care team where we had dressings and they took on a little bit, because dressings aren't high tech in palliative care, your not going to be working miracles. Whereas before we did, we had more contact or they were willing to kind of willing to look at that dressing more; ..

The PHN was in disagreement with the CNSPC role and in opposition to what the CNSPC was doing. This role conflict had resulted in a disagreement and variance to the understanding of the CNSPC role. There was a feeling of antagonism expressed by the PHN concerning the CNSPC. This was attributed to a lack of communication, most particularly if there had been a change in role. Coverman (1989) indicated that role conflict exists when persons simultaneously fulfil multiple roles. For the PHN, there was frustration, lack of shared care and conflict of role particularly as it was suggested that the role had changed. Role theory and research often suggest that role conflict might be the more dysfunctional than role ambiguity (Rizzo et al, 1970). Although Kahn et al (1964) found that when role conflict was reported that trust in persons imposing the pressure was reduced, that they liked less, they were held in lower esteem, they were less communication, and that their own effectiveness was decreased. However, Rizzo et al (1970) confirmed that many role-conflict situations were temporary but that certain positions persistently visit conflicting role pressures upon persons.

Role strain

Role strain refers to a condition when it is not possible to successfully fulfil all the expectations of the role. It then results in a stress that is generated when a person has difficulty complying with the expectations of that role (Cranford, 2013). In addition, role strain can occur when the role being filled places demands on someone. There were many contributory reasons for role strain. In an attempt to develop role theory, the knowledge that societal structures are made up of roles is known (Goode, 1960). However, role relations are a sequence of role bargains, followed by a continuing process of selection among alternative role behaviours, in which the aim is to reduce role strain (Goode 1960). When the CNSPC was unable to fulfil expectations it resulted in role strain. This related to clinical care issues concerning patient care and not being listened to by medical colleagues. Two of the CNSPC focus group interviews referred to not being heard which resulted in role strain for the CNSPC. The CNSPC concerns were not being listened to or the medical team or GP were not recognising the concerning symptoms resulting in a breakdown in team communication.

CNS U3 And sometimes you can be chasing things and chasing things and saying what you think might be the problem and it's not been heard. Like if you have somebody that you suspect, you have nothing to go on but you suspect that they have a fracture from the way they are describing or you suspect that it may be a cord compression, you know what their

disease or what their secondaries are, you may well be banging your head off the wall trying to explain why you think this and not get them in to get them scanned. It can take you days to sort that out, you just need to be listened to and it's not happening,

The implication was that there is a delay in treatment for the patient. A further implication was that the CNSPC may not be recognised as a specialist. This may be attributed to the way the CNSPC clinical concerns are being described or voiced. There was a feeling of frustration and concern for the patient. In their discussion, CNS M4 and CNS I9 suggested that the medical team were not hearing and recognising the feedback from the CNSPC. There was a breakdown in communication and lack of recognition of the language and report of the CNSPC. The implication for the CNSPC was that they were not recognised as a specialist.

*CNS M4 I suppose also our, our, Clinical assessment mightn't be
CNS I9 Hold as much weight
CNS M4 Mightn't be heard,*

The impact of role strain resulted when the CNSPC did not describe the assessment in the language required by the medical team. Alternatively, the medical team may not have recognised the specialist nature of the CNSPC. The assumptions underpinning the role strain were that there was a difficulty in the language been spoken by the CNSPC and heard by the medical team. A further assumption may be that the CNSPC role and attributes were not being recognised. This potentially results in poor team communication that may impact on the delivery of patient care. Goode (1960) concurred that the total efforts of persons, in this case the CNSPC to reduce their role strain within structural limitations directly determined the profile, structure, or pattern of the social system. The CNSPC felt subordinate and that the assessment was not adequate. With the suggested medicalisation of palliative care (van Brummen and Griffiths 2013) the medical team may believe that assessments can only be undertaken by medics. Alternatively, the CNSPC may not have the clinical assessment language required by the medical team.

In this chapter I presented the theme of role with the subthemes of role structure, role model and expressive role within the theoretical framework of role theory being mindful of the behaviours, characteristics, norms and values of the research participants. This was the third and final theme generated from the analysis of the interviews.

In the next chapter I will present a discussion of the findings of this study. In particular I will discuss the CNSPC connection with policy and association with practice. I will then consider the implications for practice. The next chapter will also present the limitations of the study and recommendations for future research.

Chapter 7 Discussion

7. 0 Introduction

The previous three chapters presented the main findings and analysis of this study. Each chapter presented a theme. These themes were i) journey, ii) aspects of care and iii) role. In this chapter I will discuss the findings of this study, what it means for the CNSPC in relation to the existing literature on the theoretical framework of role and the philosophy of palliative care. The CNSPC position within primary care (DoHC, 2001a) and the recently established CHO (HSE, 2014a) will be discussed.

In conclusion the implications for practice will be discussed and recommendations will be made. Limitations of the study will be identified. Areas for future research will be specified. The dissemination process for the findings of this study will be identified.

7.1 Role Clarification

Clinical focus was the concentrated area of practice for the CNSPC in this study. This was a thread that ran through the theme of journey, aspects of care and role. It was closely followed by the recognition for patient advocacy and to a lesser extent the focus on consultancy. What is interesting was that minimal focus was given to education, training, audit and research, although there was recognition by the CNSPC that these areas lacked input. Whereas all the CNSPC who participated in this study saw and referred to themselves as CNS, they were not undertaking and participating in the five core concepts. These core concepts were recognised as being of importance but difficulties in undertaking them were attributed to a lack of time, as the main focus of care was clinical practice.

There were varying views expressed by all participants in regards to the CNSPC time. Overwhelmingly it was welcomed by the patients and family members that the CNSPC was in a position to have time to spend with them. The majority of the CNSPC themselves, the PHN' and GPs recognised that the CNSPC had more time to spend with the patient and family. This was recognised to be of value for the patient and family at this time of care. However, one CNSPC expressed concern that there was less time available then in the past to dedicate to end of life care. While the CNSPC and PHN acknowledged each other's role, there was some tension between both nurses concerning their respective roles. Both the patients and CNSPC suggested that the PHN role was embedded in the physical aspects of care including the organising of equipment. This was in variance to the PHN perspectives of their role where they recognised a supportive

element to their role similar to the UK district nurse role perception identified by Griffith et al (2007) in supporting cancer patients with palliative care needs.

Communication issues were raised by both the CNSPC and PHN. These invariably had the potential to impact on the understanding of roles. However, communication concerns between the CNSPC and PHN were not necessarily a South of Ireland phenomenon and were highlighted by Gallagher (2013) between specialist palliative care and district nurses and were one of the themes that emerged in Mulvihill et al (2010) literature review of the role of the specialist palliative care nurse in the community.

In this study, patients and family members overwhelmingly recognised the symptom control and medication management element of the CNSPC role. This correlated with the most important elements of care being management of symptoms identified by Mitchell (2010), and similar to the patients in Chapple et al (2006) who valued the advice on symptom management. Of significance in the current study were both the patients and family member's decision to contact the CNSPC before the GP concerning symptom control and medication management issues of concern.

Similarly, there was a lack of time to attend to direct nursing care and to realise the education, audit and research element of the role while the representative of the NCNM suggested there may be a fear of audit and research. Significantly, there is an overwhelming need for role clarification by the CNSPC in these areas of care. In addition, as a resource, education, training and consultancy are all important responsibilities in facilitating the role of CNSPC. However, as recognised by the CNSPC these were not delivered at the same level as the responsibilities associated with clinical focus and patient advocate.

The CNSPC may have been clear what their role entailed, but outside factors and organisational issues were found to influence the role at times. Role clarification was of significance in this study when it came to the GP, PHN and members of the multidisciplinary palliative care teams understanding of the role. The importance and understanding of role clarification was highlighted by the representative of the NCNM where its description was necessary from the inception and development of the post. Using the Lindsmith and Strauss (1968) method Lambert and Lambert (1981) identified four key factors related to interactions that facilitated role enactment. These were of importance when considering role clarification. The first key factor was the identification of self (Lambert and Lambert, 1981) and this may not have been fully considered at role

development for the CNSPC. The position of “Home Care Nurse” had been in place when palliative care was recognised as a specialist area (Government of Ireland, 1998). Many nurses transitioned to the position of CNSPC and role development may not have been fully realised at this time. The Macmillan nurses in Skilbeck et al (2002) and Seymour et al (2002) study were also CNS’. The transition for the Macmillan nurses from the delivery of direct patient care was attributed to role ambiguity by Seymour et al (2002).

Invariably, new CNSPCs have been appointed but the change in role may not be recognised by nurse management, other healthcare professionals and the MDT and significantly have a resulting impact on realising the role. In 2002, Seymour et al recognised that the Macmillan nurses in the UK lacked the resources, organisational infrastructure and managerial support in the delivery of palliative care to patients. Similarly, the recent findings in Whittaker et al (2014) in Northern Ireland signalled the importance of management valuing staff. It has to be acknowledged that the clinical focus and patient element of the role were fully realised by all participants in the study but the remaining elements of the CNSPC role were not recognised to the same extent.

As Biddle (1986) suggested, roles reflect norms and attitudes. The role of the Home Care Nurse in the NACPC (DoHC, 2001) included the provision of information, advice and support to patients, families and healthcare professionals and could be clearly aligned to the clinical focus and patient advocate elements (NCNM, 2008) of the role of CNSPC.

7.2 Palliative Care and Primary Care

The NACPC (DoHC, 2001) is the current policy document for the delivery of the palliative care in Ireland. This specifically recognised that the specialist palliative care nurse in the community acted as a resource, support and advice to other health professionals in the community, had an advisory role in relation to symptom control and liaised between the community services and the specialist palliative care unit (DoHC, 2001). The CNSPC, in the study, acted as a resource for the GPs and PHNs in both the direct and indirect care elements of their clinical focus and patient advocate role.

Concurrently in Ireland, in 2001, a Primary Care Strategy was published by the DoHC (2001a). This health strategy proposed the introduction of an interdisciplinary team based approach to primary care with a wider primary care network to support the Primary Care Teams (PCT) (DoHC, 2001a). It was envisaged that the CNSPC as a member of the wider network of health and social care professionals would work with a number of PCTs.

To date the PCTs are in varying stages of development. Through the study none of the CNSPCs made reference to working within a Primary Care Network or attended meetings with a PCT. The GPs and one of the PHN focus groups envisaged that the CNSPC should participate in the PCTs. The DoHC (2001a) recognised that the PCT team would liaise with specialist teams in the community to improve the integration of care. Bliss et al (2000) literature review recognised the importance of inter-professional working in the delivery of a quality palliative care service in the community. However, similar to the Irish setting, Bliss et al (2000) acknowledged challenges were present in the understanding of roles and professional values.

More recently, the CHO Report and Recommendations of the Integrated Service Area Review Group was launched by the HSE (2014a). Bearing in mind the recent challenging economic environment, this report set out to progress the concepts enunciated in the Primary Care Strategy (DoHC, 2001a) through the continuing development of PCTs and Health and Social Care Networks (HSE, 2014a). It is envisaged that each Health and Social Care Network will ensure the maximum provision of primary care services locally (HSE, 2014a). In addition, the network will support appropriate access to specialised services (HSE, 2014a). This will include specialist palliative care.

The GP has overall responsibility for the medical care of patients in the community (DoHC, 2001). This includes responsibility for referral of patients to the CNSPC. It was evident from the study that GPs were concerned that patients were referred to the CNSPC too early. The DoHC (2001) recommended that palliative care should be incorporated into the patient's care plan at an early stage of the disease trajectory. This was highlighted again more recently by Ryan (2014), in a written submission to the joint committee on Health and Children, Public Hearings on End of Life. This submission noted that palliative care had expanded where it was now provided at an earlier stage in the disease trajectory. The recently established CHO (HSE, 2014a) will now provide the necessary link for the CNSPC to a number of PCTs. With the future establishment of each Health and Social Care Network, this will enhance the support from specialist service to the PCTs and the relationship with members of the PCT.

7.3 “Shared Care”

The concept of shared care was clearly demonstrated in one of the CNSPC focus group interviews and less so in the other teams. From the outset, a plan of care existed where representatives of the CNSPC and the PHN undertook a joint first visit and planned the

provision of all care following this, identifying a shared set of goals and objectives. The patient was involved in the plan and at no time was there duplication of visits. The specific value of shared care to the PHN was that self-competence and judgment of capabilities in providing quality care to patients and their families with life-limiting conditions or at the end of life was enhanced (Desbiens et al, 2011). At interview, the PHNs indicated they would welcome a shared plan of care.

The NACPC (DoHC, 2001) recommended that the concept of shared care should be promoted for the patient receiving palliative care in the community. The purpose being to avoid duplication of services and to ensure that patients were not overcrowded in their own homes as the DoHC (2001) suggested that the role of the specialist palliative care nurse frequently overlapped with the PHN. The concerns expressed by Raftery et al (1996) regarding uncoordinated services were, that they would be a duplication of services to some patients and lack of services to others. In the study the PHNs highlighted their concerns over the duplication of services in the provision of care. The improved shared care arrangements for specific health conditions were echoed by the Primary Care Strategy (DoHC, 2001a) in order to enable patients to be managed more effectively and by a more extensive range of professionals in the community. Additionally, the lack of shared care can impact on the quality of care delivered in the community as it is dependent on the effectiveness of the co-ordination between the nursing services (DoHC, 2001). There was a small element of tension concerning the delivery of care. However, for the CNSPC, the NCM (2008: 13) indicated that the direct care element of the clinical focus “includes the assessment, planning and delivery and evaluation of care to patients/ clients and families”. In addition, the study indicated that following the financial crisis, a moratorium ensued and some posts had not been filled immediately. Inevitably, as recognised by Stryker (2006), multiple role involvements can result in intrapersonal, interpersonal and intra-group conflicts.

7.4 Five Core Concepts of the Clinical Nurse Specialist Role.

Although there was a natural ease in the delivery of the clinical focus and patient advocacy aspects of the role, the CNSPC were challenged and were out of their comfort zone when faced with education and training, audit and research and consultancy. Role is the shared behavioural expectations attached to any position and Turner (1962) agreed that behaviour was the product of role making. This relates back to role clarification because as Stryker (2006) indicated the building of roles is dependent on the larger social structures where situations are embedded. Despite the fact that there was recognition by

the CNSPC that they were not attaining the five core concepts, there was no plan in place to address these issues. This had potential implications for practice where the CNSPC was not meeting the CNS competency role. From an education and training perspective, the deficits were present in the provision of mentorship, pre-ceptorship, teaching, facilitation and identification of continuing professional development needs as recognised by the NCNM (2008). Similarly, from the audit and research perspective there was a lack of identifying, analysing and disseminating evidence into the area of specialist practice or participation in audit, further competencies recognised by the NCNM (2008).

Providing a mechanism for staff development in Northern Ireland was highlighted by Whittaker et al (2014) as an impetus for management to value staff. This included both learning and development support. Participation in education activities was previously identified by Booth et al (2003) as contributing to address staff development. The current study determined that the CNSPC was not fulfilling all elements of their role. However, it was also evident that there was little formal managerial support to address this and to review each CNSPC professional development needs that could support staff development. Booth et al (2003) recognised that the support of senior colleagues influenced how specialists undertook their role. This had the potential to empower the CNSPC and contribute to addressing the elements of their role that they were not achieving. The opportunity now is to consider creative solutions through a partnership approach within the organisation and across directorates (Whittaker et al, 2014) that can facilitate individual learning and development for the CNSPC in the South of Ireland.

This can have a resulting impact for the CNSPC in the provision of leadership or acting as a potential resource and role model for specialist palliative care. In line with findings of other CNS roles in Palliative Care (Husband and Kennedy, 2006; Seymour et al, 2002) the results of this study are consistent concerning the CNSPC. Challenges were noted internationally in terms of acceptance of the CNS role by members of the multidisciplinary team (Kilpatrick et al, 2011; Lindblad et al, 2010; Norris and Melby, 2006; O'Connor, 2008; Por, 2008). The CNSPC in the study experienced some concerns in relation to their discussions with medical colleagues regarding patient's complex symptom control issues. This may be attributed to the medical colleagues understanding of the CNSPC role and less clarity on the elements of practice including education, audit and research. If, as Begley et al (2014) suggested, that challenges to the CNS role included medical fears of diminished roles or a lack of support from colleagues, the CNSPC has to demonstrate within their practice that they are specialist and expert. By addressing the individual learning and development needs of the CNSPC within a supportive environment can then

enhance confidence, skills and promote better working relationships with other health care professionals (Whittaker et al, 2014).

However, the education and training findings of the role of the current study are at variance to Elliott et al (2012) SCAPE study conducted in Ireland where CNSs/ APs were found to take responsibility for guideline development in their own area of specialist practice, implementing new guidelines through dissemination and co-ordinating reviews. Additionally, in the SCAPE study, Begley et al (2013) determined that CNSs were more likely to be involved in audit than research. The findings of the SCAPE study mean that over ten years following the establishment of clinical nurse specialism in Ireland some CNSs are achieving all the core concepts of their role and others are not. This implies that there has not been a standardised approach to role development and enactment.

7.5 Implications for Practice – Integrated Primary Care Palliative Care

This study is timely because of the recent changes to the operation of the community services in Ireland. As a member of the Health and Social Care Network, it has to be anticipated that the CNSPC will work as a resource to a number of PCTs. This means that in addition to having a responsibility for the clinical focus and patient advocate elements of care, the responsibilities associated with consultancy, education and training, audit and research will be paramount. With the establishment of the CHO (HSE, 2014a), integrated care for patients and their families, equity of access and choices for patients in what services they receive and how they receive them will be enhanced. For the CNSPC, their contribution to the Health and Social Care Network will serve to enhance the delivery of a seamless service to the patient and family.

Invariably, this will provide an opportunity for the CNSPC to maximise the quality of life for patients through prompting, promoting and improving their health and wellbeing. This can be achieved by supporting the PCTs in the identification of palliative care priority needs and inequalities within the population. A mechanism is now available for the CNSPC to ensure that health promoting palliative care can be considered at an early stage in the illness trajectory (Sepulveda et al, 2002). These developments mark a new phase in the history of palliative care, with an expansion of its initial goals to cover earlier stages of the disease trajectory (Gott et al, 2011).

An interdisciplinary team approach in the community is important in order to provide a seamless and efficient service to patients and their families (DoHC, 2001). In an effort to

facilitate this, an individual care plan, appropriate to patient needs (DoHC, 2001a) is necessary in the community where all primary care providers can work from the plan. There is a very apparent need for the management structure of both the CNSPC and the PHNs to implement the recommendations concerning shared care (DoHC, 2001; DoHC, 2001a) with agreed objectives and locally developed written guidelines. The role of the Primary Care Team in the recently established CHO (2014a) will include the development of shared care models across service provision.

Identification of CNS Role

Perhaps it is now timely for the CNSPC to address the evolving definition of the role (Biddle, 1986). Through a consultation process and with the support of their nurse managers, the CNSPC need to engage with members of the MDT and community colleagues and inform them of their role. In addition, as well as clarifying the role it will assist the CNSPC in enacting Lambert and Lambert (1981) second key factor of appropriate behaviour in given situations relevant to the role. Through the identification and confirmation of the role, the CNSPC will have the confidence to enact and practice the appropriate behaviour when discussing patients distressing and complex symptoms. The CNS will then be in a position to understand and deal with the specific action of others that serve as suggestions to guide specific conduct, assessment and evaluation. If the CNSPC has role clarity, this will impact on the behaviour in the role and how this influences the CNS' actions. Inevitably, this affects how the CNSPC behaves internally and externally to the organisation (Brooks et al, 2007). Role clarification will address a number of issues encountered by the CNS.

In conjunction with their nursing manager, the CNSPC needs to formulate a plan to facilitate individual learning and development that will integrate the consultancy, education and training, audit and research into their current role. As Desbiens et al (2011) suggests the success and motivation to act grows the more the palliative care nurse perseveres in the face of difficulties, where quality palliative care requires both nursing competence and self-competence to be used effectively. With the clarification of role and understanding by the nurse manager, a protected time plan may be agreed to facilitate individual learning and address the CNSPC professional development plan. A link to academia will enhance this process and provide the CNSPC with confidence and the skills to clearly demonstrate these expert skills in the specialist area.

CNS Five Core Concepts

The road from novice to expert has been somewhat different for some of the CNSPC where they transitioned from the role of Home Care Nurse. The role of the CNSPC was established in 2001 where the long established Home Care Nurse took on the role and learned to be an expert. Other nurses who have been appointed as CNSPC have had to meet the education and clinical experience criteria set down by the NCNM (2008).

Though the CNSPCs may have taken different routes both have experienced struggles and difficulty in being recognised as an expert or specialist. The position of CNSPC is not a standalone position but integrated with other professionals, the patient and family. Notwithstanding, a fine balance and skill is required to facilitate, not take over and avoid deskilling other health care professionals. The continuing need to entwine care, through enhancing skills and knowledge provision is necessary. Similarly, audit and research, education and training influence the delivery of evidence based practice. To influence other health care practitioners in the community, the CNSPC needs to have the evidence based knowledge and demonstrate evidence based practice to be recognised as a specialist and expert practitioner.

Each CNSPC had a job description that outlined the five core concepts and clearly indicated the competencies required for the role. However, despite the fact that a nurse is currently recognised as a CNS, there is no accreditation requirement to confirm that the competencies associated with each core concept are being achieved. As a result of the economic crisis in Ireland, the NCNM was dissolved by the then Minister for Health in 2010. At the time, the Minister signed statutory legislation (Nurse Rules, 2010) where additional functions were assigned to the Nursing and Midwifery Board of Ireland in relation to the accreditation process for the Advanced Nurse Practitioner (ANP). An interim arrangement is currently in operation for the accreditation of the CNS through the Office of the Nursing and Midwifery Services Director (ONMSD) (HSE and ONMSD, 2014). It is now timely where a measure is required for the CNS to undertake a five year review of their accreditation. This in addition will facilitate a mechanism and opportunity to address the core concepts that may be more difficult to realise.

There is ample opportunity to develop the education, audit and research element of the role of the CNSPC through role clarification and understanding of others of the contribution that the CNSPC can make. As well as a link to academia, a link to a clinical placement co-ordinator or mentor would enhance the education, audit and research element of the role. Similar suggestions were made by participants in Begley et al (2014)

to enhance the research output of the CNS role. The nurse manager is a critical person in the CNSPC role development and understanding of the role. Through understanding, the nurse manager and CNSPC will be in a position to negotiate (Lambert and Lambert, 1981) and agree protected time. This will contribute to the CNSPC development. The CNSPC has to prove and demonstrate how their expertise can be useful and beneficial and where their skilled observation (Benner and Tanner, 1987) can be noticed with expert appraisal in the delivery of specialist palliative care.

7.6 Limitations

There were a number of limitations to this research study. With only two GPs, four patients and three family members participating in the study, the number of participants was small for these groups. Three family members participated as a result of the patient requesting that the family member would not be interviewed. This resulted in only one family member participating in one of the areas. This study reflects the accounts and perspectives of the participants and my interpretation of these. This study was conducted in two of the health areas in the South of Ireland.

The study examined the role from the perspective of health care professionals in the community. However, by including the perspectives of the specialist palliative care team members may have given a broader understanding of the issues.

During the time of the study complex changes were encountered in the Irish health care system. These were compounded by the political and economical changes that occurred through the lifetime of the study. These impacted on the length of time taken to conduct and finalise the study.

I was dependent upon the CNSPC to recruit patients and family members to participate in the research. They had to consider and select who they thought would be suitable and were happy for me to interview. I had no indication that any of the CNSPCS were gatekeepers.

7.7 Suggestions for further research

This study explored the role of the CNSPC from the perspective of the health care professionals in the community but the specialist palliative care MDT were recognised as having a significant role in the delivery of palliative care in the community. Further research is needed to explore their perspectives of the role compared to the health care

professionals in the community. Further research is required into the development and expansion of the role and scope of the CNSPC. One such area of expansion is the role of the CNSPC in nurse prescribing. Advanced Nurse Practitioner (ANP) is a further advanced nursing role in Ireland. Research is needed into the difference between the role of the ANP and CNS in palliative care.

There was much reference to “shared care” but further research is required as to what it means and a broader analysis of nursing care in the community is needed.

7.8 Recommendations

- The clarification of the role of the Clinical Nurse Specialist in Palliative Care in the Community (CNSPC)
- Following clarification of the role, establish information sessions with the MDT and community colleagues identifying the role of the CNSPC.
- Through a partnership approach, consider solutions that can be realised to assist with the elements of the CNS role that are not being enacted.
- Through an interdisciplinary team approach the development of a standardised individual care plan for the palliative care patient in the community.
- Through a partnership approach between the management structure of the CNSPC and PHN, examine the area of “shared plan of care” in the community.
- The CNSPC establishes a link to an academic department.
- The CNSPC establishes a link to a clinical placement co-ordinator.
- A CNS five year accreditation process is established

7.9 Dissemination of Findings

The aim of a Professional Doctorate in Health is to make a contribution to both theory and practice in a particular field and invariably develop professional practice by making a contribution to professional knowledge. My thesis on the role of the CNSPC in the South of Ireland will contribute both to the theory and practice of palliative care nursing in this area by providing a current body of knowledge that can inform practice in the South of Ireland relevant to Palliative Care nursing in the community.

From an Irish perspective the findings of my thesis are contributing to changes and are being used to inform the recently established Palliative Care Development Framework Steering Group 2016 – 2020 in the South of Ireland. The purpose of this Development

Framework is to affect a purposeful response to the palliative care challenges and ensure adult palliative care services deliver geographically needs based, innovative, evidence based, quality driven and person centred patient care (HSE 2015). As the CNSPC is the central component to the delivery of a specialist palliative care service in the community, this thesis and its recommendations are informing the evidence base for the community element of this framework.

A steering group has been established to develop this framework, and I am a sitting member of this steering group. As a member of the steering group, I am suitably placed to disseminate, influence and progress the findings and recommendations of this thesis.

7.10 Summary

I began this thesis by setting out my background, introducing the CNS in Palliative Care in Ireland and explained why I had decided on this area of study. I then examined the development of the CNS in general and palliative care and then provided justification for my study. The format of the thesis was presented. The second chapter presented the literature review where the CNS role development globally and then pertaining to the Irish context was given. The organisational impact of the role was examined. The theoretical framework pertinent to this study was role theory. Evidence specific to the CNS in palliative care was then examined and challenges were identified. The research question, aims and objectives were presented. In chapter three the methodology and methods which guided the study were presented. The research design was guided by the philosophical underpinnings of symbolic interactionism and a qualitative approach was used. The role of the CNSPC from the participant's perspective was captured through focus group and semi structured interviews and non-participant observation. Thematic analysis was used to capture the perspectives of the participants. Rigor and reflexivity was discussed. Chapter four, five and six presented the findings and analysis of the study. Each chapter presented a different theme. Chapter four presented the theme journey as a metaphor, chapter five presented aspects of care and chapter six presented role. Chapter seven was the final chapter and discussed the findings of the study. Discussion focused on a number of areas relating to practice and policy. The implications for practice together with recommendations were discussed. The limitations of the study, suggestions for future research and dissemination of findings were presented.

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Appendices

Appendix 1 Letter to Director of Nursing inviting Clinical Nurse Specialist participation



**School for Health,
University of Bath,
Claverton Down,
Bath,
United Kingdom BA2 7AY.**

Re: Research Study

Dear (Director of Nursing/Nurse Manager)

I am currently undertaking a research study titled "The Role of the Community Clinical Nurse Specialist in Palliative Care in the South of Ireland". The purpose of this study is to identify the role of the Community Clinical Nurse Specialist (CNS) in Palliative Care/Home Care Nurse from a number of different perspectives. This includes the perspective of the Clinical Nurse Specialist in Palliative Care in the Community. The study will involve a short focus group activity lasting approximately 1 hour and the completion of a demographic questionnaire.

I would welcome the opportunity to meet with the Community CNS's in your service, explain the research study being undertaken and invite them to participate in the study.

This study also includes interpreting the role of the CNS from the perspective of the Specialist Palliative Care patient and family members. At this meeting I wish to explore the feasibility of identifying a patient and family member who would be willing to participate in this research. I am including a CNS and family information leaflet for your information and the information of the CNS's in Palliative Care.

Should you have any queries about this study I would be happy to discuss them with you and can be contacted at the above address.

If you are willing for me to talk to the CNS team I will contact you by telephone in one week to arrange a date of convenience to meet with the Community CNS in Palliative Care/Home Care Nurse team.

Yours Sincerely,

Eileen O'Leary,
Doctoral Student at the University of Bath.



**School for Health,
University of Bath,
Claverton Down,
Bath,
United Kingdom BA2 7AY.**

Community Clinical Nurse Specialist Information Leaflet

Study Title: The Role of the Community Clinical Nurse Specialist in Palliative Care in the South of Ireland

I would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. Part 1 tells you the purpose of this study and what will happen to you if you take part. Part 2 gives you more detailed information about the conduct of the study.

Part 1

What is the purpose of the study?

The purpose of this study is to identify the role of the Community Clinical Nurse Specialist in Palliative Care/ Home Care Nurse from a number of different perspectives. This study is a student research project.

Why have I been invited?

I would like to learn from your perspective, what you consider your role by asking some questions to you and some colleagues in a focus group. At separate occasions I also hope to interview some other individuals for example patients, family members, a General Practitioner, Public Health Nurses and the governing body for Clinical Nurse Specialist.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do, I will describe the study and go through this information sheet, which I will then give to you. I will then ask you to sign a consent form to show you have agreed to take part. You are free to withdraw at any time, without giving a reason or a decision not to take part.

What will happen to me if I take part?

You will be required to partake as a member of a focus group with other CNS's in Palliative Care. This interview will last for approximately one hour in total. This will be held in a location removed from your office base. Refreshments will be served prior to the focus group interview.

What are the possible disadvantages and risks of taking part?

It is not the intention of the researcher to cause any distress to you during the course of the interview. If however, for any reason you become upset, the researcher can contact a professional for you or alternatively give you a contact number for a professional support person.

In the event that issues relating to the delivery of sub-optimal practice should arise in discussion, the researcher will be required to inform the appropriate Director of Nursing/Nurse Manager.

What are the possible benefits of taking part?

The information received will help to describe your role from your perspective. The knowledge gained will allow those who deliver care to provide feedback on the care they

deliver in a manner that will assist in the training and education of CNSs. This information received will inform decision making and policy on the role of the CNS. The results of this study will inform the teaching and support of the CNSs. These benefits will ultimately lead to the delivery of enhanced patient care.

Will my taking part in this study be kept confidential?

Yes. All information about your participation in this study will be anonymised. The details are included in Part 2.

Contact Details

Researcher: Name

Contact Number:

If the information in this section has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

Part 2

What will happen if I don't want to carry on with the study?

You can withdraw from the study and if you wish you can keep in contact with me.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do their best to answer your question (phone number). If you remain unhappy and wish to complain formally, you can do this through the University of Bath Complaints Procedure.

Will my taking part in this study be kept confidential?

With your permission I will use an audio tape recorder to record our conversation. All the data collected will be stored securely. If you join the study, the data collected may be looked at by the University of Bath to check that the study is being carried out correctly. All information which is collected about you during the course of the research will be anonymised. All possible steps will be taken to treat responses as confidential. Any information about you which leaves the researcher will have your name and address removed so that you cannot be recognised from it.

Who is organising and funding the research?

This research is being conducted as part of a Professional Doctorate Programme at the University of Bath, United Kingdom and the researcher is funding the study.

Who has reviewed the study?

All research conducted through the University of Bath is reviewed by an independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has also been given favourable opinion by both Health Area 11 and Health Area 1 Research Ethics Committee.

You will receive a copy of a signed consent form to keep.

Thank you for considering taking part and taking the time to read this sheet.

Appendix 3 – Letter to Clinical Nurse Specialist Palliative Care: Patient and Family Member agree to interview



**School for Health,
University of Bath,
Claverton Down,
Bath,
United Kingdom BA2 7AY.**

Re: Research Study

Dear CNS in Palliative Care/Nurse Manager,

I am currently undertaking a research study titled “The Role of the Community Clinical Nurse Specialist in Palliative Care in the HSE South”. The purpose of this study is to identify the role of the Community Clinical Nurse Specialist in Palliative Care/ Home Care Nurse from a number of different perspectives. This includes the perspective of the Specialist Palliative Care patient.

Thank you for identifying (patients name), who has agreed to partake in this study. I would be grateful if you could forward the enclosed pack to this person for there information.

I would also be grateful if you can kindly forward the enclosed letter to the person’s General Practitioner on my behalf.

Should you require any further details regarding this study do not hesitate to contact me at (researcher number).

Yours Sincerely,

Eileen O’Leary,
Doctoral Student at the University of Bath.



**School for Health,
University of Bath,
Claverton Down,
Bath,
United Kingdom BA2 7AY.**

Re: Research Study

Dear CNS in Palliative Care/Nurse Manager,

I am currently undertaking a research study titled "The Role of the Community Clinical Nurse Specialist in Palliative Care in the South of Ireland". The purpose of this study is to identify the role of the Community Clinical Nurse Specialist in Palliative Care/ Home Care Nurse from a number of different perspectives. This includes the perspective of the Family member.

Thank you for identifying (family member name), who has agreed to partake in this study. I would be grateful if you could forward the enclosed pack to this person for there information.

Should you require any further details regarding this study do not hesitate to contact me at (researcher number).

Yours Sincerely,

Eileen O'Leary,
Doctoral Student at the University of Bath.



**School for Health,
University of Bath,
Claverton Down,
Bath,
United Kingdom BA2 7AY.**

Re: Study

Dear (Patients Name)

I am currently undertaking a research study titled "The Role of the Community Clinical Nurse Specialist in Palliative Care in the South of Ireland". The purpose of this study is to identify the role of the Community Clinical Nurse Specialist in Palliative Care/ Home Care Nurse from a number of different perspectives. This includes the perspective of the patient.

Your (identify Specialist Palliative Care Team) has kindly passed this letter to you on my behalf as I do not have your address. Thank you for considering partaking in this study. The contents include a patient information sheet and a patient consent form. These will provide further information on your involvement. Should you agree to partake in this study I will discuss any queries you may have regarding the leaflet and consent form prior to conducting the interview.

I will also be informing your General Practitioner by letter of your agreement to undertake this interview.

Should you require any further details regarding this study do not hesitate to contact me at (researcher number). I will contact your Home Care Nurse in one week to confirm if you are happy to progress with the interview.

Yours Sincerely,

Eileen O'Leary,
Doctoral Student at the University of Bath.



**School for Health,
University of Bath,
Claverton Down,
Bath,
United Kingdom BA2 7AY.**

Patient Information Leaflet

Study Title: The Role of the Community Clinical Nurse Specialist in Palliative Care in the South of Ireland

I would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. Part 1 tells you the purpose of this study and what will happen to you if you take part. Part 2 gives you more detailed information about the conduct of the study.

Part 1

What is the purpose of the study?

The purpose of this study is to identify the role of the Community Clinical Nurse Specialist in Palliative Care/ Home Care Nurse from a number of different perspectives. This study is a student research project.

Why have I been invited?

I would like to learn from your perspective, what you consider the role of the nurse is by asking you some questions through an interview. I also hope to interview some other individuals for example family members, the Community Clinical Nurse Specialist in Palliative Care/Home Care Nurse, a General Practitioner, Public Health Nurses and the governing body for Clinical Nurse Specialist.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do, I will describe the study and go through this information sheet, which I will then give to you. I will then ask you to sign a consent form to show you have agreed to take part. You are free to withdraw at any time, without giving a reason or a decision not to take part. This will not affect the standard of care you receive.

What will happen to me if I take part?

You will be required to partake in one interview which will last for approximately one hour in total.

What are the possible disadvantages and risks of taking part?

It is not the intention of the research to cause any distress to you during the course of the interview. If however, for any reason you become upset, the researcher can contact a professional for you or alternatively give you a contact number for a professional support person.

What are the possible benefits of taking part?

There will be no change to your treatment or condition having taken part in this interview. The information received will help to generate knowledge on the role of the Home Care Nurse from your perspective. This interview will allow you to provide feedback on the care

you receive in a manner that will assist in the training and education of CNSs. Ultimately, this will lead to the delivery of enhanced care.

Will my taking part in this study be kept confidential?

Yes. All information about your participation in this study will be anonymised. The details are included in Part 2 of this form.

Contact Details

Researcher: Name

Contact Number:

If the information in this section has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

Part 2

What will happen if I don't want to carry on with the study?

You can withdraw from the study and if you wish you can keep in contact with me.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do their best to answer your question (phone number). If you remain unhappy and wish to complain formally, you can do this through the University of Bath Complaints Procedure.

Will my taking part in this study be kept confidential?

With your permission I will use an audio tape recorder to record our conversation. All the data collected will be stored securely. If you join the study, the data collected may be looked at by the University of Bath to check that the study is being carried out correctly. All information which is collected about you during the course of the research will be anonymised. All possible steps will be taken to treat responses as confidential. Any information about you which leaves the researcher will have your name and address removed so that you cannot be recognised from it.

Involvement of the General Practitioner (GP)

Your GP will be notified of your agreement to participate in the interview but will not be provided with access to any data or information you provide in a recognisable form.

Who is organising and funding the research?

This research is being conducted as part of a Professional Doctorate Programme at the University of Bath, United Kingdom and the researcher is funding the study.

Who has reviewed the study?

All research conducted through the University of Bath is reviewed by an independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has also been given favourable opinion by both Health Area 11 and Health Area 1 Research Ethics Committee.

You will receive a copy of a signed consent form to keep.

Appendix 5 Family Member Information Pack



**School for Health,
University of Bath,
Claverton Down,
Bath,
United Kingdom BA2 7AY.**

Re: Study

Dear (Family Member)

I am currently undertaking a research study titled "The Role of the Community Clinical Nurse Specialist in Palliative Care in the South of Ireland". The purpose of this study is to identify the role of the Community Clinical Nurse Specialist in Palliative Care/ Home Care Nurse from a number of different perspectives. This includes the perspective of the family member.

Your (identify Specialist Palliative Care Team) has kindly passed this letter to you on my behalf as I do not have your address. Thank you for considering partaking in this study. The contents include a family information leaflet and a family consent form. These will provide further information on your involvement. Should you agree to partake in this study I will discuss any queries you may have regarding the leaflet and consent form prior to conducting the interview.

Should you require any further details regarding this study do not hesitate to contact me at (researcher number). I will contact your Home Care Nurse in one week to confirm if you are happy to progress with the interview.

Yours Sincerely,

Eileen O'Leary,
Doctoral Student at the University of Bath.



**School for Health,
University of Bath,
Claverton Down,
Bath,
United Kingdom BA2 7AY.**

Family Member Information Leaflet

Study Title: The Role of the Community Clinical Nurse Specialist in Palliative Care in the South of Ireland

I would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. Part 1 tells you the purpose of this study and what will happen to you if you take part. Part 2 gives you more detailed information about the conduct of the study.

Part 1

What is the purpose of the study?

The purpose of this study is to identify the role of the Community Clinical Nurse Specialist in Palliative Care/ Home Care Nurse from a number of different perspectives. This study is a student research project.

Why have I been invited?

I would like to learn from your perspective, what you consider the role of the nurse by asking you some questions through an interview. I also hope to interview some other individuals for example patients, the Community Clinical Nurse Specialist in Palliative Care/Home Care Nurse, a General Practitioner, Public Health Nurses and the governing body for Clinical Nurse Specialist.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do, I will describe the study and go through this information sheet, which I will then give to you. I will then ask you to sign a consent form to show you have agreed to take part. You are free to withdraw at any time, without giving a reason or a decision not to take part. This will not affect the standard of care your ill relative receives.

What will happen to me if I take part?

You will be required to partake in one interview which will last for approximately one hour in total.

What are the possible disadvantages and risks of taking part?

It is not the intention of the researcher to cause any distress to you during the course of the interview. If however, for any reason you become upset, the researcher can contact a professional for you or alternatively give you a contact number for a professional support person.

What are the possible benefits of taking part?

The information received will help to describe the role of the Home Care Nurse from your perspective. This knowledge will allow those who receive care and their families to provide feedback on that care in a manner that will assist in the training and education of

CNSs. These results will ultimately lead to the delivery of enhanced care to the patient and their family.

Will my taking part in this study be kept confidential?

Yes. All information about your participation in this study will be anonymised. The details are included in Part 2 of this form.

Contact Details

Researcher: Name

Contact Number:

If the information in this section has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

Part 2

What will happen if I don't want to carry on with the study?

You can withdraw from the study and if you wish you can keep in contact with me.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do their best to answer your question (phone number). If you remain unhappy and wish to complain formally, you can do this through the University of Bath Complaints Procedure.

Will my taking part in this study be kept confidential?

With your permission I will use an audio tape recorder to record our conversation. All the data collected will be stored securely. If you join the study, the data collected may be looked at by the University of Bath to check that the study is being carried out correctly. All information which is collected about you during the course of the research will be anonymised. All possible steps will be taken to treat responses as confidential. Any information about you which leaves the researcher will have your name and address removed so that you cannot be recognised from it.

Who is organising and funding the research?

This research is being conducted as part of a Professional Doctorate Programme at the University of Bath, United Kingdom and the researcher is funding the study.

Who has reviewed the study?

All research conducted through the University of Bath is reviewed by an independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has also been given favourable opinion by both Health Area 11 and Health Area 1 Research Ethics Committee.

You will receive a copy of a signed consent form to keep.

Thank you for considering taking part and taking the time to read this sheet.

Appendix 6 Letter to GP patient agree to interview



**School for Health,
University of Bath,
Claverton Down,
Bath,
United Kingdom BA2 7AY.**

Re: (Name Person)

Dear Dr (Name General Practitioner)

I am currently undertaking a research study titled "The Role of the Community Clinical Nurse Specialist in Palliative Care in the South of Ireland". The purpose of this study is to identify the role of the Community Clinical Nurse Specialist in Palliative Care/ Home Care Nurse from a number of different perspectives. This includes the perspective of the Specialist Palliative Care patient.

The (identify Specialist Palliative Care Team) identified you as the person's General Practitioner and kindly forwarded this letter to you on my behalf.

(Patient's name) has agreed to partake in this study which will involve an interview in the patient's home. This will last approximately one hour.

I enclose details of the patient information leaflet and patient consent form for your attention.

Should you require any further details regarding this study do not hesitate to contact me at (researcher number).

Yours Sincerely,

Eileen O'Leary,
Doctoral Student at the University of Bath.

Appendix 7 Letter to Director of Public Health Nursing inviting Public Health Nurses Participation



**School for Health,
University of Bath,
Claverton Down,
Bath,
United Kingdom BA2 7AY.**

Re: Research Study

Dear (Director of Public Health Nursing)

I am currently undertaking a research study titled "The Role of the Community Clinical Nurse Specialist in Palliative Care in the South of Ireland". The purpose of this study is to identify the role of the Community Clinical Nurse Specialist (CNS) in Palliative Care/ Home Care Nurse from a number of different perspectives. This includes the perspective of the Public Health Nurse (PHN). The study will involve a short focus group activity lasting approximately 1 hour.

I would welcome the opportunity to meet with the Public Health Nurses in your service, explain the research study being undertaken and invite them to participate through focus group interviews.

Should you have any queries about this study I would be happy to discuss them with you and can be contacted at the above address.

If you are willing for me to talk to the PHNs I will contact you by telephone in one week to arrange a date of convenience to meet with the Public Health Nurses.

Yours Sincerely,

Eileen O'Leary,
Doctoral Student at the University of Bath.



**School for Health,
University of Bath,
Claverton Down,
Bath,
United Kingdom BA2 7AY.**

Public Health Nurse Information Leaflet

Study Title: The Role of the Community Clinical Nurse Specialist in Palliative Care in the South of Ireland

I would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. Part 1 tells you the purpose of this study and what will happen to you if you take part. Part 2 gives you more detailed information about the conduct of the study.

Part 1

What is the purpose of the study?

The purpose of this study is to identify the role of the Community Clinical Nurse Specialist (CNS) in Palliative Care/ Home Care Nurse from a number of different perspectives. This study is a student research project.

Why have I been invited?

I would like to learn from your perspective, what you consider the role of the CNS by asking some questions to you and some PHN colleagues in a focus group. At separate occasions I also hope to interview some other individuals for example patients, family members, Community CNS's in Palliative Care, a General Practitioner and the governing body for Clinical Nurse Specialist.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do, I will describe the study and go through this information sheet, which I will then give to you. I will then ask you to sign a consent form to show you have agreed to take part. You are free to withdraw at any time, without giving a reason or a decision not to take part.

What will happen to me if I take part?

You will be required to partake as a member of a focus group with other PHN's. This interview will last for approximately one hour in total. This will be held in a location removed from your office base. Refreshments will be served prior to the focus group interview.

What are the possible disadvantages and risks of taking part?

It is not the intention of the researcher to cause any distress to you during the course of the interview. If however, for any reason you become upset, the researcher can contact a professional for you or alternatively give you a contact number for a professional support person.

What are the possible benefits of taking part?

The information received will help to describe the role of the Community Clinical Nurse Specialist in Palliative Care from your perspective. The knowledge gained will allow those who deliver care to provide feedback on the care they deliver in a manner that will assist in the training and education of CNSs. This information will inform decision making and

policy on the role of the CNS. The results of this study will inform the teaching and support of the CNSs. These benefits will ultimately lead to the delivery of enhanced care to the patient and family.

Will my taking part in this study be kept confidential?

Yes. All information about your participation in this study will be anonymised. The details are included in Part 2.

Contact Details

Researcher: Name

Contact Number:

If the information in this section has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

Part 2

What will happen if I don't want to carry on with the study?

You can withdraw from the study and if you wish you can keep in contact with me.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do their best to answer your question (phone number). If you remain unhappy and wish to complain formally, you can do this through the University of Bath Complaints Procedure.

Will my taking part in this study be kept confidential?

With your permission I will use an audio tape recorder to record our conversation. All the data collected will be stored securely. If you join the study, the data collected may be looked at by the University of Bath to check that the study is being carried out correctly. All information which is collected about you during the course of the research will be anonymised. All possible steps will be taken to treat responses as confidential. Any information about you which leaves the researcher will have your name and address removed so that you cannot be recognised from it.

Who is organising and funding the research?

This research is being conducted as part of a Professional Doctorate Programme at the University of Bath, United Kingdom and the researcher is funding the study.

Who has reviewed the study?

All research conducted through the University of Bath is reviewed by an independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has also been given favourable opinion by both Health Area 11 and Health Area 1 Research Ethics Committee.

You will receive a copy of a signed consent form to keep.

Thank you for considering taking part and taking the time to read this sheet.



**School for Health,
University of Bath,
Claverton Down,
Bath,
United Kingdom BA2 7AY.**

Re: Research Study

Dear Irish College of General Practitioner,

I am currently undertaking a research study titled "The Role of the Community Clinical Nurse Specialist in Palliative Care" in the South of Ireland. The purpose of this study is to identify the role of the Community Clinical Nurse Specialist in Palliative Care/ Home Care Nurse from a number of different perspectives. This includes the perspective of the General Practitioner.

One of the methods of data collection in this study includes interviews with one General Practitioner from Health Area 1 and one from Health Area 11. I would be most grateful if you can identify General Practitioners in both these areas that I may contact to conduct such an interview. I am including a General Practitioner information leaflet for your information.

Should you require any further details regarding this study do not hesitate to contact me at (researcher number).

I will contact you by telephone in two weeks time.

Yours Sincerely,

Eileen O'Leary,
Doctoral Student at the University of Bath.



**School for Health,
University of Bath,
Claverton Down,
Bath,
United Kingdom BA2 7AY.**

General Practitioner Information Leaflet

Study Title: The Role of the Community Clinical Nurse Specialist in Palliative Care in the South of Ireland

I would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. Part 1 tells you the purpose of this study and what will happen to you if you take part. Part 2 gives you more detailed information about the conduct of the study.

Part 1

What is the purpose of the study?

The purpose of this study is to identify the role of the Community Clinical Nurse Specialist (CNS) in Palliative Care/ Home Care Nurse from a number of different perspectives. This study is a student research project.

Why have I been invited?

I would like to learn from your perspective, what you consider the role of the CNS by asking some questions to you. At separate occasions I also hope to interview some other individuals for example patients, family members, Community CNS's in Palliative Care, Public Health Nurses and the governing body for Clinical Nurse Specialist.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do, I will describe the study and go through this information sheet, which I will then give to you. I will then ask you to sign a consent form to show you have agreed to take part. You are free to withdraw at any time, without giving a reason or a decision not to take part.

What will happen to me if I take part?

You will be required to partake in one interview in a location of your choice. This interview will last for approximately one hour in total.

What are the possible disadvantages and risks of taking part?

It is not the intention of the researcher to cause any distress to you during the course of the interview. If however, for any reason you become upset, the researcher can contact a professional for you or alternatively give you a contact number for a professional support person.

What are the possible benefits of taking part?

The information received will help to describe the role of the Community Clinical Nurse Specialist in Palliative Care from your perspective. The knowledge gained will allow those who deliver care to provide feedback on the care they deliver in a manner that will assist in the training and education of CNSs. This information will inform decision making and policy on the role of the CNS. The results of this study will inform the teaching and support of the CNSs. These benefits will ultimately lead to the delivery of enhanced care to the patient and family.

Will my taking part in this study be kept confidential?

Yes. All information about your participation in this study will be anonymised. The details are included in Part 2.

Contact Details

Researcher: Name

Contact Number:

If the information in this section has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

Part 2**What will happen if I don't want to carry on with the study?**

You can withdraw from the study and if you wish you can keep in contact with me.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do their best to answer your question (phone number). If you remain unhappy and wish to complain formally, you can do this through the University of Bath Complaints Procedure.

Will my taking part in this study be kept confidential?

With your permission I will use an audio tape recorder to record our conversation. All the data collected will be stored securely. If you join the study, the data collected may be looked at by the University of Bath to check that the study is being carried out correctly. All information which is collected about you during the course of the research will be anonymised. All possible steps will be taken to treat responses as confidential. Any information about you which leaves the researcher will have your name and address removed so that you cannot be recognised from it.

Who is organising and funding the research?

This research is being conducted as part of a Professional Doctorate Programme at the University of Bath, United Kingdom and the researcher is funding the study.

Who has reviewed the study?

All research conducted through the University of Bath is reviewed by an independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has also been given favourable opinion by both Health Area 11 and Health Area 1 Research Ethics Committee.

You will receive a copy of a signed consent form to keep.

Thank you for considering taking part and taking the time to read this sheet.

Appendix 10 Letter to Senior Nurse at the National Council for the Professional Development of Nursing and Midwifery inviting participation



**School for Health,
University of Bath,
Claverton Down,
Bath,
United Kingdom BA2 7AY.**

Re: Research Study

Dear Senior Nurse with responsibility for CNS at NCNM,

I am currently undertaking a research study titled "The Role of the Community Clinical Nurse Specialist in Palliative Care" in the South of Ireland. The purpose of this study is to identify the role of the Community Clinical Nurse Specialist in Palliative Care/ Home Care Nurse from a number of different perspectives. This includes the perspective of a representative of the Clinical Nurse Specialist division of the National Council for the Professional Development of Nursing and Midwifery. I would like to invite you to participate in this research study.

I will contact your office by telephone in two weeks time to discuss questions you may have and discuss the feasibility of partaking in an interview. I attach an information leaflet for your attention.

Should you require any further details do not hesitate to contact me at (researcher number).

Yours Sincerely,

Eileen O'Leary,
Doctoral Student at the University of Bath.



**School for Health,
University of Bath,
Claverton Down,
Bath,
United Kingdom BA2 7AY.**

Representative with responsibility for CNS at NCNM

Study Title: The Role of the Community Clinical Nurse Specialist in Palliative Care in the South of Ireland

I would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. Part 1 tells you the purpose of this study and what will happen to you if you take part. Part 2 gives you more detailed information about the conduct of the study.

Part 1

What is the purpose of the study?

The purpose of this study is to identify the role of the Community Clinical Nurse Specialist (CNS) in Palliative Care/ Home Care Nurse from a number of different perspectives. This study is a student research project.

Why have I been invited?

I would like to learn from the perspective of the NCNM, what you consider the role of the CNS by asking some questions to you. At separate occasions I also hope to interview some other individuals for example patients, family members, Community CNS's in Palliative Care, Public Health Nurses and General Practitioners.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do, I will describe the study and go through this information sheet, which I will then give to you. I will then ask you to sign a consent form to show you have agreed to take part. You are free to withdraw at any time, without giving a reason or a decision not to take part.

What will happen to me if I take part?

You will be required to partake in one interview in a location of your choice. This interview will last for approximately one hour in total.

What are the possible disadvantages and risks of taking part?

It is not the intention of the researcher to cause any distress to you during the course of the interview. If however, for any reason you become upset, the researcher can contact a professional for you or alternatively give you a contact number for a professional support person.

What are the possible benefits of taking part?

The information received will help to describe the role of the Community Clinical Nurse Specialist in Palliative Care from the perspective of the NCNM. The knowledge gained will allow those who receive and deliver care to provide feedback on the care they receive and deliver in a manner that will assist in the training and education of CNSs. This information will inform decision making and policy on the role of the CNS. The results of this study will inform the teaching and support of the CNSs. These benefits will ultimately lead to the delivery of enhanced care to the patient and family.

Will my taking part in this study be kept confidential?

Yes. All information about your participation in this study will be anonymised. The details are included in Part 2.

Contact Details

Researcher: Name

Contact Number:

If the information in this section has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

Part 2**What will happen if I don't want to carry on with the study?**

You can withdraw from the study and if you wish you can keep in contact with me.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do their best to answer your question (phone number). If you remain unhappy and wish to complain formally, you can do this through the University of Bath Complaints Procedure.

Will my taking part in this study be kept confidential?

With your permission I will use an audio tape recorder to record our conversation. All the data collected will be stored securely. If you join the study, the data collected may be looked at by the University of Bath to check that the study is being carried out correctly. All information which is collected about you during the course of the research will be anonymised. All possible steps will be taken to treat responses as confidential. Any information about you which leaves the researcher will have your name and address removed so that you cannot be recognised from it.

Who is organising and funding the research?

This research is being conducted as part of a Professional Doctorate Programme at the University of Bath, United Kingdom and the researcher is funding the study.

Who has reviewed the study?

All research conducted through the University of Bath is reviewed by an independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has also been given favourable opinion by both Health Area 11 and Health Area 1 Research Ethics Committee.

You will receive a copy of a signed consent form to keep.

Thank you for considering taking part and taking the time to read this sheet.

Appendix 11 Community Clinical Nurse Specialist in Palliative Care: Focus Group Interview Schedule

Aims and Objectives

- To identify the Community Clinical Nurse Specialists in Palliative Care perspective of their role
- To establish the support measures needed for the Community Clinical Nurse Specialist in Palliative Care to fulfil their role
- To identify the challenges the Community Clinical Nurse Specialist in Palliative Care encounter as they attempt to fulfil their role

Key questions for focus groups (CNS)

- Number of participants _____
 - General atmosphere of the session?
 - Other observations of interest?
1. Can you identify the key functions of your role?
 2. Can you outline what distinguishes your as a Community CNS in Palliative Care?
 - a. How might your role be different from the public health nurse for example?
 3. Do you think there are any essential personal qualities that you need for role?
 4. Are there any aspects of your role that you feel you would like to develop further (Probe – what is the impetus for this i.e. personal development or an expectation of the organisation or the NCNM?)
 5. Do you think you make a difference to the care specialist palliative care patients and families receive? (Probe – In what way? How do you determine this?)
 6. Can you reflect on any support measures that you have available to you that are helpful in fulfilling your role? (Probe – what else would make a difference?)
 7. Do you encounter any in your role?
 - a. If so what are they?

CONFIDENTIAL

Q1. Please indicate to which age group you belong

25-29

30-34

35-39

40-44

45-49

50-54

55-59

60-64

Q2. Please indicate are you:

Male

Female

Q3. Which of the following pathways describes your access to receiving recognition as Clinical Nurse Specialist in Palliative Care?

Immediate Route (In recognition of those nurses and midwives already functioning as CNSs/CMSs CNS with 5 years experience in the relevant specialist area)

--

Intermediate Route (All CNS/CMS applicants with 2 years experiences in the relevant specialist area and have undertaken a higher/postgraduate diploma in a relevant subject area or enter a contractual agreement to pursue to pursue such programme)

--

Q3. Please list your educational qualifications i.e. at Certificate, Diploma, Degree, Post Graduate Diploma, Masters and PHd level.

- 1.**
- 2.**
- 3.**
- 4.**

Q4. Please list all professional development you have undertaken in the past 2 years and its duration:

Duration

- 1.**

- 2.
- 3.
- 4.

Q5. Please list all education and training you have delivered in the past two years and the recipients:

Recipients

- 1.
- 2.
- 3.
- 4.

Q6. Please list all audits you have undertaken in the past two years:

- 1.
- 2.

Q.7 Please list the performance outcome measures you record?

- 1.
- 2.
- 3.
- 4.

Q7. Do you have a personal development plan?

Yes

No

Don't know

Q8. Do you complete an annual report on your activities?

Yes

No

Don't Know

Thank you for completing

Appendix 13 Patient Interview Schedule

Aims and Objectives

- To identify the specialist palliative care patients perspective of the role of the Community Clinical Nurse Specialist in Palliative Care/Home Care Nurse
- To explore the specialist palliative care patients understanding of the role of the Community Clinical Nurse Specialist in Palliative Care/Home Care Nurse
- To explore the specialist palliative care patient's views on the contribution the Community Clinical Nurse Specialist in Palliative Care/Home Care Nurse makes to their care.

Key questions for semi-structured interview

- Location interview held
 - Observations of interest?
1. I'm here today to talk to you about the Home Care Nurse, has she been visiting you recently?
 2. How many times has she been here with you?
 3. How did you feel about her visiting you and your family?
 4. Can you tell me what do you think the Home Care Nurses job involves?
 5. Do you have other nurses visiting you at present? Is the Home Care Nurses role different from the other nurses who visit you?
 6. Can you tell me what happens during a visit?
 7. Do you think the Home Care Nurse has made a difference to your care and treatment since she visited at first? (Probe-in what way?)
 8. Can you tell me about her involvement with your family/main carer?
 9. Do you think there is anything else that the Home Care Nurse could do that would help you at present?
 10. Is there anything else you would like to say or any question you would like to ask me?

Appendix 14 Family member Interview Schedule

Aims and Objectives

- To identify the family members perspective of the role of the Community Clinical Nurse Specialist in Palliative Care/Home Care Nurse
- To explore the family members understanding of the role of the Community Clinical Nurse Specialist in Palliative Care/Home Care Nurse
- To explore the family member's views on the contribution the Community Clinical Nurse Specialist in Palliative Care/Home Care Nurse makes in assisting them to care for the specialist palliative care patient.

Key questions for semi-structured interview

- Location interview held
 - Observations of interest?
1. I understand the Home Care Nurse been visiting your ill relative recently, have you met her during these visits?
 2. Can you tell me from what do you think the Home Care Nurses job involves?
 3. Do you have other nurses visiting at present? Can you tell me is the Home Care Nurses role different from the other nurses who visit you?
 4. Can you tell me what happens during a visit for your ill relative and for you?
 5. Do you think the Home Care Nurse has made a difference to the care and treatment of your ill relative since she first visited? (Probe-in what way?)
 6. Can you tell me about the difference to you?
 7. Do you think there are any specific qualities that would be important for the job of Home Care Nurse?
 8. Do you think there is anything else that the Home Care Nurse could do that would help you at present?
 9. Is there anything else you would like to say or any question you would like to ask me?

Appendix 15 Public Health Nurses Focus Group Interview Schedule

Aims and Objectives

- To explore the Public Health Nurses perspective of the role of the Community Clinical Nurse Specialist in Palliative Care.
- To explore the Public Health Nurses understanding of the role of the Community Clinical Nurse Specialist in Palliative Care.
- To explore the Public Health Nurses views on the contribution the Community Clinical Nurse Specialist in Palliative Care makes to their own role.

Key questions for focus groups (Public Health Nurse)

- Number of participants _____
 - General atmosphere of the session?
 - Other observations of interest?
1. Can you identify the key functions of the role of the Community Clinical Nurse Specialist in Palliative Care?
 2. Do you think there are any essential qualities needed for this role?
 3. Do you think the Community Clinical Nurse Specialist makes a difference to the care of the specialist palliative care patient? (Probe - If none, why not, if yes how is this measured?)
 4. Can you reflect on how the Community Clinical Nurse Specialist in Palliative Care assists you most in the community setting?
 - a. Can you give some examples?
 5. Are there any areas that the Community Clinical Nurse Specialist in Palliative Care could help you in your role?
 - a. Can you suggest some examples?(Probe – what difference would this make? How could this be achieved?)

Appendix 16 General Practitioner Interview Schedule

Aims and Objectives

- To explore the General Practitioner perspective of the role of the Community Clinical Nurse Specialist in Palliative Care.
- To explore the General Practitioner understanding of the role of the Community Clinical Nurse Specialist in Palliative Care.
- To explore the General Practitioner views on the contribution the Community Clinical Nurse Specialist in Palliative Care makes to their own role.

Key questions for semi-structured interview

- Location interview held _____
 - Other observations of interest?
1. Have you worked with the Community CNS in Palliative Care recently?
 2. Do you find you work frequently with the Community CNS in Palliative Care?
 3. Can you tell me what kind of an experience has this been?
 4. From your experience what do you identify as the key functions of the role of the Community CNS in Palliative Care?
 5. Do you think there are any personal qualities needed for this role?
 6. Do you think the Community CNS makes a difference to the care of the specialist palliative care patient? (If none, why not, if yes explore how do you measure this?)
 7. The Community CNS in Palliative Care is suppose to operate where he/she observes a role in clinical focus, as patient advocate, in education and training, in research and audit and as a consultant. From your experience would you agree with this? If yes explore, if no why?
 8. Does the Community CNS in Palliative Care make a difference to you in the community setting?
 - a. How can you give examples of this?
 9. Do you think there are any areas that the Community CNS in Palliative Care could help more/less in your role? (Probe – what difference would this make? How could this be achieved?)

Appendix 17 Representative of the National Council for the Professional Development of Nursing and Midwifery Interview Schedule

Aims and Objectives

- To identify from the NCNM perspective the role of the Community Clinical Nurse Specialists in Palliative Care
- To explore the NCNM understanding of the role of the Community Clinical Nurse Specialist in Palliative Care.
- To establish the support measures needed for the Community Clinical Nurse Specialist in Palliative Care to fulfil their role
- To identify the challenges the Community Clinical Nurse Specialist in Palliative Care encounter as they attempt to fulfil their role

Key questions for semi-structure interview

- Location interview held _____
 - Other observations of interest?
1. I'm here today to talk to you about the Community Clinical Nurse Specialist in Palliative Care; can you describe from the NCNM perspective what is a Community CNS in Palliative Care?
 2. What would be the key functions of this role?
 3. What difference do you think the Community Clinical Nurse Specialist in Palliative Care can make to the total care of the specialist palliative care patients? (Probe – in what way do you determine this)
 4. Do you think that there are any specific essential personal qualities that are necessary for this role? (Probe – what makes you think that?)
 5. Are there any aspects of the role that could be developed further? Can you give examples? (Probe – why would you say that?)
 6. What support measures are necessary and helpful in fulfilling this role? (Probe – what else could make a difference)
 7. From your experience what challenges are CNS's experiencing in their role?

Appendix 18 University of Bath Ethical Approval

From: Vicki Buckley [mailto:vjeb20@bath.ac.uk]
Sent: 14 August 2009 11:59
To: O'Leary, Eileen
Subject: Re: ++SPAM++ RE: ++SPAM++ FW: ++SPAM++ RE: Feedback from SREAP

Hi Eileen,

Sorry for the delay in replying to you. You will be pleased to hear that SREAP have now granted ethical approval for your project 'The role of the Community Clinical Nurse Specialist in Palliative Care in the south of Ireland'. I will send a formal letter to confirm SREAP approval shortly.

Best wishes,
Vicki

>>> _____
>>> Dr Vicki Buckley
>>> School Administrator
>>> School for Health
>>> University of Bath
>>> Claverton Down
>>> Bath, BA2 7AY
>>>
>>> Tel: 01225 383368
>>> Fax: 01225 383833
>>> Email: V.J.E.Buckley@bath.ac.uk
>>> _____

Appendix 19 Clinical Research Ethics Committee Health Area 1

COISTE EITICE UM THAIGHDE CLINIÚIL
Clinical Research Ethics Committee

Ireland

Our Ref. ECM 3 (tt) 07/04/09

16th March 2009

Dr Paula Smith
Senior Lecturer
Dept of Psychology
University of Bath
Claverton Down
Bath BA2 7AY
UK

Re: The role of the community clinical nurse specialist in palliative care in the South of Ireland.

Dear Dr Smith

The Chairman approved the following:

➤ Signed Application form.

Full approval is now granted to carry out the above study.

Yours sincerely





Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

Health Service Executive
100, St. James's Gate
Dublin 8, Ireland.

Telephone 051 848000
Fax 051 848572

NAME Ms. Eileen O'Leary
ADDRESS 8 Marlstone Manor
Thurles
Co. Tipperary
DATE 3rd June 2009

RESEARCH ETHICS COMMITTEE.
HEALTH SERVICE EXECUTIVE, SOUTH EASTERN AREA

Study Title:

"The role of the Community Clinical Nurse Specialist in Palliative Care in the South of Ireland"

Dear Ms O'Leary

The Research Ethics Committee, HSE, South East reviewed the above study at the meeting on the: **23rd March 2009**

The study was: **Approved** ☒

Approved with Conditions ☐

Not approved ☐

The REC reviewed and approved the following documents:

- | | |
|--|-------------------------------------|
| 1. (✓) Ethics Application Form | 8. () Investigator brochure |
| 2. (✓) Protocol/ Research Proposal | 9. (✓) Investigator(s) CV (s) |
| 3. () Amendment | 10. () Investigators MDU/Insurance |
| 4. (✓) Participant Information Leaflet | 11. (✓) Sponsor insurance |
| 5. (✓) Participant Consent Form | 12. () Funding for the study |
| 6. (✓) Recruitment Literature | |
| 7. (✓) Indemnity Form | |

Health Service Executive Mission Statement:
"Together we will provide quality patient care delivered by skilled and valued staff through the best use of available resources".

Appendix 21 Community Clinical Nurse Specialist Consent Form



**School for Health,
University of Bath,
Claverton Down,
Bath,
United Kingdom BA2 7AY.**

Community Clinical Nurse Specialist Identification Number:

Consent Form

Title of Project: **The Role of the Community Clinical Nurse Specialist in Palliative Care in the South of Ireland**

Name of Researcher: **Eileen O'Leary**

Please initial
box

- 1 I confirm that I have read and understand the information sheet dated ☐
(version.....) for the above study. I have had the opportunity to consider the information,
ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time
without giving any reason, without my legal rights being affected. ☐
3. I understand that relevant sections of the data collected during the study, once ☐
anonymised, may be looked at by individuals from the University of Bath where it is
relevant to my taking part in this research. I give permission for these individuals to have
access to my records.
4. I understand that an audio tape recorder will be used to record our conversation. ☐
5. I agree to take part in the above study ☐

Participant

Date

Signature

Name of Researcher

Date

Signature

When completed, 1 for community clinical nurse specialist in palliative care; 1 for
researcher site file;

Appendix 22 Patient Consent Form



School for Health,
University of Bath,
Claverton Down,
Bath,
United Kingdom BA2 7AY.

Patient Identification Number:

Consent Form

Title of Project: **The Role of the Community Clinical Nurse Specialist in Palliative Care in the South of Ireland**

Name of Researcher: **Eileen O'Leary**

Please initial
box

- 1 I confirm that I have read and understand the information sheet dated ☐
(version.....) for the above study. I have had the opportunity to consider the information,
ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time ☐
without giving any reason, without my medical care or legal rights being affected.
3. I understand that relevant sections of the data collected during the study, once ☐
anonymised, may be looked at by individuals from the University of Bath where it is
relevant to my taking part in this research. I give permission for these individuals to have
access to my records.
4. I understand that an audio tape recorder will be used to record our conversation. ☐
5. I agree that my GP will be informed of my agreement to participate in the study. ☐
6. I agree to take part in the above study ☐

Participant

Date

Signature

Name of Researcher

Date

Signature

When completed, 1 for patient; 1 for researcher site file;

Appendix 23 Family Member Consent Form



School for Health,
University of Bath,
Claverton Down,
Bath,
United Kingdom BA2 7AY.

Family Member Identification Number:

Consent Form

Title of Project: **The Role of the Community Clinical Nurse Specialist in Palliative Care in the South of Ireland**

Name of Researcher: **Eileen O'Leary**

Please initial
box

- 1 I confirm that I have read and understand the information sheet dated ☐
(version.....) for the above study. I have had the opportunity to consider the information,
ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time ☐
without giving any reason, without my legal rights being affected.
3. I understand that relevant sections of the data collected during the study, once ☐
anonymised, may be looked at by individuals from the University of Bath where it is
relevant to my taking part in this research. I give permission for these individuals to have
access to my records.
4. I understand that an audio tape recorder will be used to record our conversation. ☐
5. I agree to take part in the above study ☐

Participant

Date

Signature

Name of Researcher

Date

Signature

When completed, 1 for family member; 1 for researcher site file;

Appendix 24 Public Health Nurse Consent Form



School for Health,
University of Bath,
Claverton Down,
Bath,
United Kingdom BA2 7AY.

Public Health Nurse Identification Number:

Consent Form

Title of Project: **The Role of the Community Clinical Nurse Specialist in Palliative Care in the South of Ireland**

Name of Researcher: **Eileen O'Leary**

Please initial
box

- 1 I confirm that I have read and understand the information sheet dated ☐
(version.....) for the above study. I have had the opportunity to consider the information,
ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time ☐
without giving any reason, without my legal rights being affected.
3. I understand that relevant sections of the data collected during the study, once ☐
anonymised, may be looked at by individuals from the University of Bath where it is
relevant to my taking part in this research. I give permission for these individuals to have
access to my records.
4. I understand that an audio tape recorder will be used to record our conversation. ☐
5. I agree to take part in the above study ☐

Participant Date Signature

Name of Researcher Date Signature

When completed, 1 for public health nurse; 1 for researcher site file;

Appendix 25 General Practitioner Consent Form



School for Health,
University of Bath,
Claverton Down,
Bath,
United Kingdom BA2 7AY.

General Practitioner Identification Number:

Consent Form

Title of Project: **The Role of the Community Clinical Nurse Specialist in Palliative Care in the South of Ireland**

Name of Researcher: **Eileen O'Leary**

Please initial
box

- 1 I confirm that I have read and understand the information sheet dated ☐
(version.....) for the above study. I have had the opportunity to consider the information,
ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time ☐
without giving any reason, without my legal rights being affected.
3. I understand that relevant sections of the data collected during the study, once ☐
anonymised, may be looked at by individuals from the University of Bath where it is
relevant to my taking part in this research. I give permission for these individuals to have
access to my records.
4. I understand that an audio tape recorder will be used to record our conversation. ☐
5. I agree to take part in the above study ☐

Participant Date Signature

Name of Researcher Date Signature

When completed, 1 for General Practitioner; 1 for researcher site file;

Appendix 26 Representative of the National Council for Nursing and Midwifery Consent Form



**School for Health,
University of Bath,
Claverton Down,
Bath,
United Kingdom BA2 7AY.**

Representative with Responsibility for Clinical Nurse Specialists at the NCNM:

Consent Form

Title of Project: **The Role of the Community Clinical Nurse Specialist in Palliative Care in the South of Ireland**

Name of Researcher: **Eileen O'Leary**

Please initial
box

- 1 I confirm that I have read and understand the information sheet dated ☐
(version.....) for the above study. I have had the opportunity to consider the information,
ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time ☐
without giving any reason, without my legal rights being affected.
3. I understand that relevant sections of the data collected during the study, once ☐
anonymised, may be looked at by individuals from the University of Bath where it is
relevant to my taking part in this research. I give permission for these individuals to have
access to my records.
4. I understand that an audio tape recorder will be used to record our conversation. ☐
5. I agree to take part in the above study ☐

Participant

Date

Signature

Name of Researcher

Date

Signature

When completed, 1 for NCNM; 1 for researcher site file;

Chival Nurse Specialist Four Group Interview

Appendix 27 - ^{for ledger} Manual Coding of Transcripts

<p>Challenge - will all, ^{for ledger}</p> <p>Travel Journey - patient family</p> <p>Challenge - dying not nice</p> <p>Acknowledged dying / talk about dying Different focus Presence</p>	<p>have a huge life before they ever met you, a lot of things going on and dynamics, you are not going to repair or fix, you just have help them to guide them through it,</p> <p>R. So you travel with the patient ,</p> <p>Travel, ya,</p> <p>Through there journey you know,</p> <p>R. Through there journey,</p> <p>And there families,</p> <p>Between them,</p> <p>And you know the dying isn't always nice, you're keeping your head, sometimes you know, we want it to be all nice and giving permission for that. That's where you support the other agencies.</p> <p>R. So sometimes the experience of dying may not be what people expect,</p> <p>And I suppose the corollary of that,</p> <p>That's ok,</p> <p>And the corollary of that, we are the first specialty where, that the patient is likely to have met, where cure is not the intention, so it's a really very different perspective and we are coming with a very different perspective, so I hope that our presence there makes its very clear that we are prepared to talk about these things, that suddenly aren't so taboo anymore. Because our focus is very different, our focus isn't on cure its on dying well,</p> <p>And our presence is a big thing because that's what each one of us brings, valuing that,</p> <p>R. So you mentioned the obviously whole area of presence, your focus is different to what everybody else focus has been up to the time they actually meet yourselves, the continuity of care and the trust, the trust that people have to build up, with yourselves and ye with them, and you also spoke about the research and the importance of updating yourselves and the involvement with the multidisciplinary team. So I'm going to move on to the next question, if that is ok,</p>
<p>R. Can you outline what distinguishes you as a community CNS in Palliative Care and how your role might differ from other nurses in the community?</p> <p>Multidisciplinary team.</p> <p>Narrow focus perception of other disciplines</p> <p>Broad focus - challenge</p> <p>Conflict narrow band</p> <p>Support - access to nursing</p>	<p>We have the advantage of coming back and meeting the multidisciplinary team, that the others haven't, and discussing it with them.</p> <p>We would have a very narrow, like the public health nurse would have to deal with all aspects of patients where we have a very narrow focus,</p> <p>And that's a bit paradoxical actually, even though like our focus is on end-of-life care or the end stages of serious illnesses, yet in ways we have a broader focus because we take in all of the different aspects of there life as well. We're worried about there family circumstances, we're worried about their medical card, and so, we don't have to do the vaccinations, we don't look at the baby,</p> <p>Dressings as well</p> <p>And so we don't do dressings, and so its much, much narrower, but then in other aspects it's much broader,</p> <p>But when we go in then, it's much broader,</p> <p>We have much more support, we have access to a consultant, all the other, oncology reg,</p>

P2. I can share everything with them and I mean that from the bottom of my heart, I could share anything with the girls.

R. So when you got sick first, were they involved at that stage?

P2. Shortly after they were involved, shortly after the girls were involved with me you know, after the operation. To be honest with you I didn't really know. It was one of the nurses in C (Location Acute General Hospital) in oncology, she said to me "you have a Home Care Team in D (Location of Home) and would you like them to call to you". I says to her, sure "ya" I had the nurses from the clinic coming. But like that's a different thing altogether like you know; and then she said, "do you mind if the Home Care Team visit P2 "she said and I said "sure they can come". It changed me life when the girls came, it did because I feel safe. And that safeness means everything, you know.

R. That was great, absolutely.

P2. I was delighted that they did come into my life, to tell you the truth. So they come in at any time and they are there for me, like you know.

R. So that makes a big different?

P2. Oh, an awful difference, to know that there is someone there for you when you are so sick, you know. The girls they are so good like and they know what to give you like. What's right for you, you know.

R. I know ya. And you mentioned about the nurses from the clinic,

P2. Ya

R. So there are obviously other nurses that have been calling to you as well. Would you think there job is different now to the Home Care Nurses job?

P2. I do, I do.

R. In what way would the jobs differ?

P2. Well, I think meself that the Home Care Team does a lot more to be honest with you. They are involved in you life a lot more, they do more for ya, and the Home Care Team does everything for me, like. The nurses from the clinic now just asks me a few questions, just ask me "how I am" and that then. Don't get me wrong, they are lovely nurses.

R. I know, I know.

P2. I wouldn't say anything about them. They are grand nurses. They are lovely women coming into your home, but its completely different altogether. They are different nurses

NCHM Interview

R. So, I suppose, what support measures are necessary and helpful in fulfilling this role as community clinical nurse specialists in palliative care?

N. We have kind of touched on that already in the sense that, you know the support mechanisms are; Well first of all, again like anything else, it is a continuum, so that when a new CNS goes into post, and if they are the first in that area in the community, then they will need a huge amount of support. They need it from their medical colleagues. In the acute services all of the negotiations will have to have been put in place, the CNS might have to do that themselves, they need there, you know they need there, they need there reporting relationships clearly outlined; there, the key, the key to successful role in regards the new role is for everybody understands what the new role is about. If the CNS roles are confused and roles are blurred the barriers go up. OK, so the clarity of roles is key. Ok, so support structures, you can't have enough. However; if you take it down the other end of the continuum; where you have a team of clinical nurse specialists in palliative care in the community for years; that CNS will probably slip in very quickly and very easily because it is already established. So you have a continuum, you couldn't just say well everyone needs x, y and z because it's a bit like your patient needs. It depends what is already in service but certainly one of the other things I would like to see from a support point of view is link to the third level. That every clinical nurse specialist or a group of clinical nurse specialists have you know twice yearly meetings with some kind of a mentor or supervisee in a third level who can help with such; doing data, doing reviews, and actually undertaking audit/ research. So that is something that hasn't happened. It happened with ANP's up to a point but certainly that would be a fantastic advantage, certainly in the current climate and where the third levels are seeking you know;

R. That's right, so for the teams really this mentor or supervisee;

N. Absolutely, they are working within the compliments of a multidisciplinary team. That is the most important thing and that everybody on that team has bought into it and understands the role and if there is a new CNS goes into that role, part of her post will be to explain what there role and function is, and if members don't understand; I think we are beyond that in practice now, I think the role of the CNS is well embedded in Ireland. There are probably still pockets where it needs to be I don't know, where you look at the geographical spread, we could give you that, we could give you the geographical spread so ya, so like everything else;

R. And I suppose that obviously is something that would be very helpful from the audit and research point of view and meeting that need.

N. It would;

R. Is there any other support measures that would be helpful for those teams that are there for a long period of time now?

PHN Focus Group Interview

<p><i>Knows the boundaries</i></p> <p><i>Guide</i></p>	<p>PHN And And it comes around initially, without being</p> <p>PHN Gentle Gentle with them or you know, not wanting to rush in with information, they mighten be ready, yet deep down they know it, but they are not willing to express it themselves,</p> <p>PHN Well Well, it is very sensitive working, for everyone you know,</p> <p>R. And just even recapping on what ye see as the key functions of the role, are to support the family, pain and symptom control, that knowledge around medication, interaction of different medication, liaising with the GP and with the Public Health Nurse, education and that sharing of information, sharing of information with families and with health care professionals as well and knowledge, being sensitive I suppose to peoples needs, family and patients, and providing accurate information to people involved who might need, who might want more information at a particular time in a patients illness. And would you think in general that kind of covers the key functions of the role?</p> <p>PHN They They are able to judge the timing of the death much better then we would, the patients, the relatives are always asking questions "how long have we?" I mean, I find it very difficult to judge because you are only going in sporadically, you know. Whereas, I think ye have much better knowledge base then that, you know; which is great too, because they need that. They really need kind of a guide so that families can take care of a loved one at home.</p> <p>R. I know that, the accuracy around that time,</p>
<p>R. I suppose just moving on to the next question that I have here, and I suppose "do you think that the home care nurse makes a difference in care of the patient that they are actually looking after?"</p>	<p>R. I suppose just moving on to the next question that I have here, and I suppose "do you think that the home care nurse makes a difference in care of the patient that they are actually looking after?"</p>
<p><i>Specialist knowledge</i></p> <p><i>Understanding the process</i></p> <p><i>Strategic Plans</i></p> <p><i>Crossing the threshold</i></p> <p><i>Getting involved</i></p> <p><i>Extending</i></p> <p><i>Extending</i></p>	<p>Without Without a doubt,</p> <p>By By the issues that we already mentioned,</p> <p>R. Going back to those issues,</p> <p>All All those;</p> <p>We We are not trained professionally you know,</p> <p>You You know there is an expert in the house that is accessible. I think that is very important because usually they only get an appointment sporadically or whatever, <i>besides coming & travel</i> whereas if there have somebody there to talk to them they can develop a relationship, they can ask certain questions and gain more information,</p> <p>It It depends on what time, like you might have a young family, like I have a young man at the moment with three young kids; they came there early enough so she could talk to all of them and explain to them. I mean you are in and out with them sometimes, you know, whereas they can all individually meet with the Home Care and they know that. Its fabulous you know,</p> <p>R. And it could happen in the home?</p> <p>Ya Ya, in the home, private sessions, like she allocated them all a time in the family,</p> <p>R. So, it made a difference for that family,</p> <p>Thinking Thinking of that family, it made a difference to them, you know, and they were all different ages, they meet all different ages, so you know, young and old,</p> <p>Maybe Maybe they are not rushed either, in my experience, they have time, well not that you have, you know. We could be rushing, not rushing, we could give them a certain length of time but we are not there all of the time, which is nice you know,</p> <p>They They can allocate the amount of time if they need to, you know,</p> <p>They They can meet each other, they have meetings every morning, haven't they,</p> <p>R. Ya,</p> <p>From From the structure of the local team, they have very good, they have good back up service, good support for both medical and social work, they have team meetings which is wonderful, so</p>

Appendix 28 – Theme, subtheme and codes for Journey as a metaphor

Journey as a Metaphor	Travelling through the journey	Beginning the Journey
		Crossing the Threshold
		Being Companion and Traveller
		Challenges
	Connection	Getting to Know
		Listening
		Orchestrating the Progress
		Trust
	Direction	Guide
		Path
		Destination

Appendix 29 – Theme Subtheme and codes for Aspects of Care

Aspects of Care	Team	Teamwork
		Team Player
		Team Challenge
	Caring	Ordinariness/ Extraordinariness of care
		Being there
		Shared Care
		Hidden cost of caring
	Supporting	Social Support
		Triangle of care

Appendix 30 – Theme, Subtheme and code for Role

Role	Role structure	Expected Role
		Enacted Role
		Role Ambiguity
	Role Model	Professional Development
		Specialist Knowledge
		Audit and Research
	Expressive Role	Affect Attunement
		Role Conflict
		Role Strain